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The Influence of Proximal Processes in Recruitment and Participation of Monolingual Spanish-speaking Latinos/as Living with HIV in Neuropsychological Research in Milwaukee: An Ecological Theory Analysis from a Chicano Cultural Perspective.

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THE INFLUENCE OF PROXIMAL PROCESSES IN RECRUITMENT AND
PARTICIPATION OF MONOLINGUAL SPANISH-SPEAKING LATINOS/AS LIVING
WITH HIV IN NEUROPSYCHOLOGICAL RESEARCH IN MILWAUKEE: AN
ECOLOGICAL THEORY ANALYSIS FROM A CHICANO CULTURAL PERSPECTIVE

by

Enrique I. Gracian

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ABSTRACT

THE INFLUENCE OF PROXIMAL PROCESSES IN RECRUITMENT AND PARTICIPATION OF MONOLINGUAL SPANISH-SPEAKING LATINOS/AS LIVING WITH HIV IN NEUROPSYCHOLOGICAL RESEARCH IN MILWAUKEE: AN ECOLOGICAL THEORY ANALYSIS FROM A CHICANO CULTURAL PERSPECTIVE

by

Enrique I. Gracian

The University of Wisconsin-Milwaukee, 2019
Under the Supervision of Professor: Katie E. Mosack, PhD

The goal of the original study was to examine the relationships among neuropsychological measures, laboratory measures of medication management ability, self-report and pharmacy refill records, and biometric information in monolingual Spanish-speaking Latinos/as living with HIV. The researcher experienced difficulties with recruitment and collecting valid and complete data from patients who enrolled in the study. After a one-year recruitment period and with the support of the dissertation committee and advisor, the researcher changed the focus of the dissertation to examine the data that were collected using a case study framework (Berk, 2000; Bronfenbrenner, 1977, 1979). The researcher used Bronfenbrenner Ecological Systems model to guide the qualitative case study application of the problems with recruitment, difficulties collecting valid and complete data from patients who did enroll and detail the steps the investigator took to trouble shoot study difficulties during its active period with the pool of participants as the unit of analysis. Data were triangulated from different perspectives under a mixed, explanatory and exploratory, design (Baxter and Jack, 2008). Firstly, the researcher analyzed the quantitative data that included demographics, patient HIV variables, progression of disease and complications, neuropsychological data, and results from self-report

measures. Then, the investigator conceptualized qualitative information that was gathered through the screening procedure, interviews, brief conversations, and final thoughts during the study session. Data from personal observations at recruitment events and meetings with case managers and the clinic director were obtained and utilized to understand the context in which the patients interact. Finally, the investigator compared current findings to the literature in barriers to research recruitment in Spanish-speakers, and other variables that affected participation, recruitment, and acquisition of valid data. Together, this information allowed the researcher to draw conclusions about the possible dynamics at play with the findings. Further, the researcher provided suggestions for best practices in recruitment and collecting valid data from populations that are difficult to recruit.

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DEDICATION

For Us

*Muerta de miedo, tras mi coraza no permitía que nadie entrara
Tu apostaste a que te amara y vi mi futuro desde tu cara
Y de repente, solté mis amarras volé, te fuiste conmigo y en ti me quede
Y hoy mírame.*

*Se puede renacer aun después de morir,
se puede dar la vida, volviendo a vivir
Se puede todo y más junto a ti lo aprendí,
hoy sé que nada es imposible
Cuando se ama como tú.*

Pandora

*Lo que no sabes es que a mi lado es más larga la primavera
Y que el otoño con mi amor es más dorado
Y que el invierno tiene el fuego de mi abrazo
Lo que no sabes, lo que no sabes que en tus batallas soy escudo que te cuida
Que en tus heridas soy eso que cauteriza
Que no hay derrota que haga que yo no te siga
Lo que no sabes, lo que no sabes es lo que pierdes si me pierdes, pierdes tanto*

Gloria Trevi

*We can't go back
We can't undo what's done
A place to rest your head, I hope you find one
I forgive as you forget too much
When you look back on us, would you call that love?*

*When you look back on love do you think of us?
When it's all said and done is it all enough?
When you weigh the loss to all you've gained, tell me does it all add up?
When you look back on us, would you call that love?*

Kelly Clarkson

*Outgrown my past and I've shed my skin
Letting it go and I'll start again, start again
Never look back, it's a waste of time
I said, 'Oh yeah, this is me
And I'm right here where I wanna be'
I said, 'Oh yeah, this is me
Right where I'm supposed to be'*

*So, I took the road less traveled by
And I barely made it out alive
Through the darkness somehow, I survived
Tough love, I knew it from the start
Deep down in the depth
Of my Rebel Heart.*

Madonna

Para Nosotros

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Chapter 1 - Introduction

The Influence of Proximal Processes in Recruitment and Participation of Monolingual Spanish-speaking Latinos/as Living with HIV in Neuropsychological Research in Milwaukee: An Ecological Theory Analysis from a Chicano Cultural Perspective.

In the United States, over one million people are currently living with Human immunodeficiency virus (HIV) and each year more than 50,000 cases are newly diagnosed (CDC, 2013). HIV is thought to affect the central nervous system (CNS) rapidly after initial infection, resulting in persistent cognitive impairments in approximately 30-60% of individuals in the early stages (Grant, 2008). The early spread of HIV to the CNS is mostly detected based on deficits observed on neuropsychological tests since less is known about the exact timing and mechanism in which HIV crosses the blood brain barrier (BBB; Cherner et al. 2002). The usual pattern of cognitive deficits is typically consistent with abnormalities in frontal and subcortical areas that has a negative impact on cognitive domains such as attention, concentration, learning and memory, executive function, processing speed, and psychomotor speed, although inter-individual impairments vary (Reger et al., 2002; Woods et al. 2009). Despite non-uniformity in cognitive changes, researchers have attempted to group and organize neurocognitive impairments related to HIV using a nomenclature consisting of a dysfunction spectrum that ranges from subtle to clinically significant deficits that could severely interfere with activities of daily living such as employment, medication management, financial management and medication adherence (Gorman et al., 2009; Griffin et al., 2015; Woods et al. 2009). However, it appears that some activities of daily living are affected even when cognitive deficits are not clinically severe. For instance, impairments on medication management laboratory measures resulting from cognitive dysfunction related to HIV have been observed even in individuals who are virally suppressed

and thus could serve as a barrier to medication adherence abilities (Albert et al., 2003; Albert et al., 1999; Frain et al., 2014; Patton et al., 2012; Thames et al., 2011; Thames et al., 2013).

Latinos/as are more than twice as likely as non-Hispanic Whites to be living with HIV (CDC, 2009). HIV operates by attacking the immune system and if left untreated could develop into Acquired Immunodeficiency Syndrome (AIDS), a condition in which infected individuals could succumb to opportunistic infections such as the common cold and the flu virus and die (G Elfaki, 2014). When HIV was first identified, infection was highly likely to lead to death due to a lack of treatment options (Hogg et al., 2008). For instance, since HIV was recognized in 1981 about 675,000 deaths have been linked to the virus (CDC, 2016). Despite advances in prevention, diagnosis, and treatment, more than 15,000 deaths are still attributed to HIV infections on a yearly basis; in Latinos/as accounted for 8,494 new infections from a total of 38,739 new infections in 2017 (CDC, 2017). With early diagnosis and strict adherence to antiretroviral therapy (ART), life expectancy is prolonged, quality of life is enhanced, and development to AIDS is stalled (Hogg et al., 2008; Jacquet et al., 2013; Rosen et al., 2009). However, Latinos living with HIV have reported greater non-adherence to ART compared to non-Hispanic white patients (Silverberg et al., 2009; Sullivan et al., 2007), though the relationships among neurocognition, medication mismanagement laboratory measures, and medication adherence have not been examined in this population. Moreover, researchers report that neurocognitive deficits resulting from HIV infection might persist despite strict ART adherence (Griffin et al., 2015; Heaton et al., 2015), suggesting that both HIV and ART might affect the peripheral nervous system (PNS) and CNS non-uniformly (Tozzi et al., 2007).

Several investigations have been carried out to examine the relationships among neurocognition, medication management ability, and medication adherence (Andrade et al., 2012; Ettenhofer,

2010; Ettenhofer et al., 2009; Patton et al., 2012; Thames et al., 2011; Thames et al., 2013; Woods et al. 2009) in predominately White English-speaking people living with HIV. More recently, researchers have examined the association between self-reported medication adherence and brain function in Latino and Black clinical populations (Baghikar et al., 2019; Margolis et al., 2009). Evidence exists that suggests that Latino/as are significantly less adherent to antiretroviral medications (Silverberg et al., 2009; Sullivan et al., 2007) and recently Marguine and colleagues (2018) reported that Latinos, especially Puerto Ricans, have increased rate of neurocognitive impairments compared with non-Hispanic Caucasian individuals, and they call for additional investigations of social, cultural, genetic, psychological, and neuroscientific factors to understand these findings (Marguine et al., 2018).

In the following sections, the researcher will describe the need to investigate neurocognition and medication adherence in monolingual Spanish-speaking individuals living with HIV. For instance, first, he will focus molecular and cellular changes occurring during HIV infection, and present mechanisms of how HIV crosses the BBB. Then, the current and evolving neuropsychology of HIV infection and classification of neurocognitive disorders will be discussed. Next, he will discuss the relationships among neurocognition, medication adherence, and barriers to medication adherence in the context of HIV treatment. The investigator will then propose the need for an investigation of the relationships among neurocognition, laboratory measures of medication management ability, and medication adherence in the context of HIV treatment in a monolingual Spanish-speaking Latino/a population.

HIV Infection in the Peripheral and Central Nervous Systems

HIV causes complex changes in the host's cellular structure that eventually affect the efficiency of the immune system (Cowley, 2001). For example, when HIV enters the body, the human T cell protein CD4 is used as a receptor for the HIV protein gp120. The binding of gp120 onto CD4 causes changes in HIV surface proteins that allow it to blend with the human T cell membrane via CCR5 and CXCR4 co-receptors. Once binding occurs, the virus begins infecting CD4 T cells, macrophages, and dendritic cells via apoptosis, direct viral killing of infected cells, and killing of infected CD4 cells (Carter and Ehrlich, 2008). The levels of CD4 cells are particularly important because sufficient CD4 decline could make the body especially susceptible to opportunistic infections such as the common cold and the flu virus (G Elfaki, 2014).

HIV immediately begins affecting the coronary and peripheral nervous systems. However, less is known about how HIV initially crosses the BBB and begins causing changes in the CNS, although this crossing is thought to occur in the very early stages of HIV infection (Annunziata, 2003). For example, researchers have reported the presence of anti-HIV protein antibodies in the cerebrospinal fluid (CSF) of the brain, suggesting the presence of HIV infection, in both asymptomatic HIV-positive individuals who have either been treated or never been treated for HIV with ART (Andersson et al., 1998; Anderson et al., 2000; Gisolf et al., 2000; Goudsmit et al., 1986). Further, some researchers have also been able to isolate SIV (the animal equivalent to HIV) from CSF in asymptomatic SIV-positive rhesus monkeys (Chakrabarti et al., 1991). Still, other researchers have found presence of HIV in the CNS by use of post-mortem situ polymerase chain reaction (PCR) analysis of brains of asymptomatic HIV-positive men and women (An et al., 1996). More research is needed to elucidate the potency of BBB

crossing mechanisms, but it is clear that traces of HIV are found in CNS biomarkers despite asymptomatic HIV status and previous ART treatment.

Research with non-human animals has elucidated a potential mechanism in which HIV crosses the BBB. Researchers posit that HIV penetrates the CNS early by hiding within macrophage cells or as free virions causing subtle but significant changes in the structure and function of the BBB (Sharer et al., 1988). In essence, HIV infections make the BBB more permeable by attacking the structures and cells that protect it (Annunziata, 2013). For instance, there is evidence that serum proteins, usually absent in the brain, have been detected post-mortem in neurons, glia, and extracellular spaces of HIV-positive individuals in early stages of infection (Petito and Cash, 1992; Rhodes, 1991). Another hypothesis is that HIV penetrates endothelial cells that compose the BBB. Direct penetration and infection of endothelial cells in BBB has been reported in humans, by HIV, and non-human subjects by the simian immunodeficiency virus (SIV; Edinger et al., 1997; Mankowski et al., 1994; Moses et al., 1993). This penetration occurs via the CCR5 and CXCR5 coreceptor mechanisms that are bound by gp120 cells (Poland et al., 1995).

Once HIV crosses the BBB, it leads to many changes at the cellular level that eventually affect system and cognitive functions (Meeker et al., 2011). For example, when HIV enters the CNS it begins causing inflammation that facilitates the expansion of HIV infection (Haase, 1986). Typically, in the normal brain, neuroinflammation is assuaged by microglial cells that serve as workhorses that provide structural support, insulation, and repair (Ehlers and Polleux, 2010). However, HIV infects glial cells rendering them inefficient and unable to perform repair or neuroprotective mechanisms that may lead to premature aging and brain dysfunction at the functional and cognitive level in HIV-positive individuals (Meeker et al., 2011; Persidsky, et al.,

1999). Specifically, researchers have recently reported neuronal and myelin sheath loss in HIV-infected brains; these structural changes have been thought to be related to cortical atrophy and activational brain dysfunction in people living with HIV, as discussed below (Holt et al., 2012; Wright et al., 2015).

Researchers have examined structural and functional brain integrity in patients living with HIV in the post antiretroviral medication era (Holt et al., 2012). A morphometric analysis using Magnetic Resonance Imaging (MRI) in HIV-positive individuals revealed volumetric loss in the caudate, amygdala, hippocampus, and corpus callosum (Chiang et al., 2007; Chang et al., 2011; Harezlak et al., 2011). Other groups that compared HIV-positive individuals to seronegative participants found that seropositive individuals showed smaller gray matter volumes in the frontal, inferior and posterior temporal, parietal, and cerebellar regions (Becker et al., 2011; Towgood et al., 2011). Using diffusion tensor imaging (DTI), which is a more sensitive MRI technique in examining and detecting white matter abnormalities in HIV-positive patients, researchers identified the loss of white matter soon after HIV infection (Chang et al., 2008; Holt et al., 2012). Specifically, lower FA levels and other white matter abnormalities were documented by investigators in HIV-positive participants taking antiretroviral medication who initially appeared to have normal brains according to MRI images (Pomara et al., 2001). Another research group found that, at a 1-year follow-up, a group of neuroasymptomatic HIV participants showed higher MD in frontal and parietal white matter, putamen and genu compared to baseline, suggesting white matter abnormalities compared to controls (Chang et al., 2008). In general, the results revealed that HIV infection was a predictor of structural brain volume decline as measured by MRI compared to seronegative controls.

The previous evidence suggests that HIV infects glial cells and leads to neuroinflammation and apoptosis, which in turn, affects the structure of single neurons and systems of neurons. Sufficient structural changes related to HIV could eventually lead to brain functional impairments that produce negative effects on neurocognition (Kaul et al., 2005). Functional Magnetic Resonance Imaging (fMRI) is a systematic way to measure neuronal function integrity indirectly as it detects brain activity while subjects are resting or performing a task that can be completed while lying still. Researchers have examined brain function in HIV-positive individuals taking antiretroviral medication using fMRI (Holt et al., 2012; Wang et al., 2015). The findings suggest that HIV infected individuals have lower activation in the attentional network compared to seronegative controls (Chang et al., 2004). Conversely, investigators have also found abnormal hyperactivity in the lateral prefrontal cortex and the reserve brain networks in HIV infected individuals compared to seronegative controls (Ernst et al., 2002). These results are important because research groups have reported that neuroinflammation, as measured by elevated glial metabolites, in HIV-positive individuals is related to higher Blood-oxygen-level dependent (BOLD) signals as measured by fMRI (Arthurs and Boniface, 2002). Thus, BOLD signal changes are thought to be related to molecular mechanisms that indirectly affect neuronal activity. In summary, fMRI researchers suggest that HIV-infected brains could show changes in activation and less efficient network activity that attenuate capacity and cognition compared to seronegative controls despite antiretroviral treatment (Holt et al., 2012).

Since the HIV virus affects the structure of the brain in a systematic way, the alterations have similar effects on cognitive capabilities across individuals who are HIV-positive. Before the antiretroviral era, cognitive deficits appeared to be very pronounced and similar to various forms of dementias that plague individuals in advanced ages (Griffin et al., 2015; Woods et al., 2009).

However, as we will see in the forthcoming sections, with the use of antiretroviral medications, cognitive effects appear to be less severe, although they could still present from very early on after becoming infected with HIV (Sacktor et al., 2002). The molecular, structural, and functional alterations that were previously discussed have a significant effect at the cognitive level in individuals living with HIV despite antiretroviral treatment (Holt et al., 2012). Next, the researcher will discuss the neuropsychology of HIV and some specific neurocognitive disorders resulting from HIV infection.

Diagnosis of HIV-Associated Neurocognitive Disorders (HAND)

Since the beginning of the AIDS epidemic, medical practitioners noticed abnormal neuropsychological and neurological symptoms in patients with HIV infection and AIDS that remained even in the post antiretroviral era. Subsequently, a nomenclature has been developed to characterize neurocognitive disorders at various stages of HIV infection and AIDS. HIV-Associated Neurocognitive Disorders (HAND) have been separated into Asymptomatic Neurocognitive Impairment (ANI), Mild Neurocognitive Disorder (MND), and HIV-Associated Dementia (HAD; Griffin et al., 2015; Woods et al., 2009). Some researchers have suggested that HAND and HAD rates could be higher in Latinos living with HIV suggesting that race and ethnicity could be an important factor in diagnosing HAND; although most diagnostic work related to HAND was completed with English-speaking patients of various ethnicities (Rivera Mindt et al., 2008; Wojna et al., 2006). In order to successfully diagnose, or classify, any of the disorders that fall within the HAND nomenclature in the post antiretroviral medication era, at least five areas of cognitive functioning known to be affected by HIV must be examined in the absence of current severe psychopathology and substance use disorders (SUD). Ideally, these

domains must be assessed with standardized neuropsychological batteries, in addition to measures specifically developed to examine HIV-associated impairment (Grant, 2008). Furthermore, the patient's everyday functioning and adaptability is also considered when determining a diagnosis of HAND (Gorman et al., 2009; Morgan and Heaton, 2009).

Comprising 21-30% of all cases ANI is the mildest form of HAND (Robertson et al., 2007) and reflects subtle neurocognitive impairments on standardized neuropsychological measures but no deficits in everyday functioning (Griffin et al., 2015; Woods et al., 2009). Specifically, a neuropsychological battery should reveal cognitive impairments in at least two domains without interfering with activities of daily living. MND is the next level of severity in HAND, composing 30-40% of HAND diagnoses (Robertson et al., 2007). To diagnose MND, mild-to-moderate neurocognitive impairment must be reflected in at least two cognitive domains (Griffin et al., 2015; Woods et al., 2009). Neurocognitive impairment, as measured by neuropsychological tests, must be accompanied by mild deficits in everyday functioning. Generally, everyday functioning is determined by self- or proxy-report of declines in at least two activities of daily living, unemployment or reduction in job responsibilities, decrease in vocational functioning or great effort required to achieve the same level of work prior to onset, or significant impairment on laboratory measures of everyday functioning (Woods et al., 2009).

The most severe form of HAND is HAD, which is marked by moderate-to-severe cognitive impairment in at least two cognitive domains and accompanied by significant declines in activities of daily living (Griffin et al., 2015; Woods et al., 2009). A HAD diagnosis must include at least two of the following criteria: a) unemployment resulting from cognitive impairment, b) self- or proxy-report of dependence in more than 2 activities of daily living related to cognitive problems, c) self- or proxy-report of deficits in more than 4 cognitive ability

areas in everyday life, or d) significant impairments on performance-based laboratory measures of everyday functioning. Before antiretroviral medications were used, HAD was estimated to affect 6-30% of individuals (Maj et al., 1989). However, in the post antiretroviral medication era HAD has been estimated to only affect 4-7% of persons (Grant and Atkinson, 1999), with more recent statistics suggesting 1-2% (Grant et al., 2005). The progression across HAND is not as clear-cut as in other neurocognitive disorders, such as in Alzheimer's disease. Many factors, such as psychopathology and substance use comorbidities, and especially adherence to medication, are important in determining the course of HAND (Tedaldi et al., 2015; Woods et al., 2009).

As mentioned previously, the course of HAND varies across HIV-infected individuals, and the inconsistency in neuropsychological profiles makes it challenging to diagnose and recognize in the post antiretroviral medication era (Griffin et al., 2015). Similarly, it is difficult to determine cognitive deficits exclusively related to HAND as HIV-related pathology is not restricted to certain brain areas as is often found in other disorders, such as Alzheimer's disease (Querfurth and Laferla, 2010). Nonetheless, there is evidence that HAND, and specifically HAD, share many similarities to the early phases of subcortical dementias, such as Huntington's and Parkinson's disease, especially in the deficits in motor skills, processing, speed, learning and memory and executive functions (Woods et al., 2009).

Researchers have reported movement abnormalities in patients diagnosed with HAND. Severe problems, such as chorea, myoclonus, dyskinesia, and dystonia can sometimes emerge in HAD, although they are less emergent in ANI and MDN (Mirsattari et al., 1999). As such, individuals with HAD often show deficits in psychomotor measures often used to assess patients with suspected Parkinson's disease (Valcour et al., 2008). Researchers have found that bradykinesia, or slowed movement, and bradyphrenia, slowed information processing, are the

most prominent neuropsychological features of HIV and AIDS that could be used to distinguish from other disorders (Hardy and Hankin, 2002). Motor retardation, often measured by gait velocity, finger tapping, and manual dexterity (Carey et al., 2004; Heaton et al., 1995; Robertson et al. 1996), has been observed in early forms of HAD, whereas other authors have indicated that bradykinesia and bradyphrenia are important symptoms across HAND, even in patients who are virally suppressed, not just HAD (Woods et al., 2009). General processing speed deficits may also be measured with tasks that could require motor skills. The reason for discussing motor and processing speed concurrently is that motor deficits are often exacerbated by processing demands, and vice versa. Ultimately, there are difficulties in evaluating motor capabilities as movement problems may arise from various conditions and may be confounded by specific task demands. To ameliorate this issue, however, specific tests tailored to HIV-related impairments have been developed to facilitate the diagnostic criteria for movement and processing speed abnormalities, although more research validating these measures is still necessary (Igor et al., 2008; Morgan et al. 2008).

In this section the researcher discussed the typical neuropsychological profile of patients with HAND and identified psychomotor and processing speed as especially important when examining the relationships between HIV infection and neurocognition (Hardy and Hankin, 2002; Valcour et al., 2008; Woods et al., 2009). Additionally, the researcher summarized the current nomenclature used to diagnose HAND and identified challenges related to diagnosis. In the following sections, he will detail how other cognitive abilities, such as executive functions and learning and memory, are affected by HIV infections despite ART treatment, often resulting in HAND diagnoses. The investigator will also discuss how executive functions and learning and memory domains affect activities of daily living in people with HAND.

The Effect of HIV on Neuropsychological Domains

Executive functions are complex problem-solving abilities related to planning, organization, set-shifting, and inhibition (Mega and Cummings, 1994). It is thought that most executive functions are dependent on frontal cortices (Jiang et al., 2015), especially the dorsolateral frontal cortex, basal ganglia and posterior parietal areas (Stuss and Levine, 2002). Executive functions are typically measured with standardized neuropsychological tests. For example, deficits in abstraction or problem solving are often measured with the Wisconsin Card Sorting Test and the Stroop Color Word Test (Heaton et al., 1995). Set shifting is often measured with Wisconsin Card Sorting Test and Trail Making Test (Reger et al., 2002). Executive function is an important domain in which patients with HAND often have impairments (Morgello et al., 2014; Woods et al., 2009); it has also been cited as being especially deficient in Latinos/as living with HIV (Rivera Mindt et al., 2008; Wojna et al., 2006). HAND is associated with deficits in executive function, especially in the later stages of disease (Reger et al., 2002). Research samples of people living with HIV, with 30-56% of participants with undetectable viral loads, show deficits in neuropsychological tests compared to seronegative individuals (Woods et al., 2009).

Learning and memory deficits are thought to be one of the most sensitive indicators of HAND besides psychomotor abilities (Carey et al., 2004; Morgello et al., 2014; Woods et al., 2009) and could be predictive of increased need for social services due to challenges in activities of daily living such as obtaining and maintaining employment (Umaki et al., 2013). Impairments in episodic memory have been reported on visuospatial and verbal standardized measures such as the California Verbal Learning Test, Hopkins Verbal Learning Test, and Brief Visuospatial Memory Test in research samples of people with HIV consisting of up to 60% of participants who were not virally suppressed (Fazeli et al., 2014; Scott et al., 2011; Seider et al., 2014; Wang

et al., 2015), and tend to be exacerbated with progression of HIV infection (Reger et al., 2002; Scott et al., 2006). Episodic memory deficits have also been linked to lower levels of hormones that influence brain development and function in people living with HIV with undetectable viral loads (Huang et al., 2007). Generally, episodic memory deficits related to HIV infection are due to encoding or retrieval failures despite the inter-individual performance variability (Delis et al., 2000; Murji et al., 2003). These deficits are mostly observed on immediate and delayed recall components of standardized measures (Scott et al., 2011; Wang et al., 2015; Woods et al., 2005), although recognition memory impairments are detected in some more advanced cases of HAND (Delis et al., 1995). Another component of the learning and memory domain that is often impaired in HAND is prospective memory, the ability of remembering to remember (Zogg et al., 2012). Researchers have also suggested that prospective memory could be highly dependent on frontal lobe systems that are important for executive function, since its multifaceted construct requires the creation, maintenance, retrieval and execution of future intended actions (Coulehan et al., 2014; Woods et al., 2007). Prospective memory deficits have been observed in people living with HIV in laboratory tests (Bechara et al., 2007; Grant et al., 2006; Coulehan et al., 2014) and on measures of daily functioning (Woods et al., 2007) in research samples with up to 54% of participants who are virally suppressed. Further, deficits in prospective memory have predicted poor medication management (Woods et al., 2007) and medication adherence (Woods et al., 2009; Zogg et al., 2012) in people living with HIV. Nonetheless, reported prospective memory complaints from people living with HIV who are virally suppressed are only mildly related to performance-based deficits which suggests it could be difficult for individuals to accurately understand their prospective memory capabilities or dysfunction (Coulehan et al., 2014; Woods et al., 2007).

In summary, executive function and learning and memory (Coulehan et al., 2014; Morgello et al., 2014) abilities are compromised in HAND as measured by standardized tests and performance-based tests of activities of daily living even when samples consist of approximately equal numbers of participants with undetectable as well as detectable viral loads (Wang et al., 2015; Woods et al., 2009). Executive functioning and memory domains might interact with one another when completing complex activities (Hopcroft et al., 2013) such as medication management and treatment adherence (Patton et al., 2012; Zogg et al., 2012), making it difficult to disentangle deficits independently related to one domain (Woods et al., 2008). Furthermore, deficits in learning and memory could be predictive of a future need for social services resulting from an inability to adequately attend to activities of daily living such as employment (Umaki et al., 2013). Research investigating how executive functions and learning and memory deficits lead to functional impairments in everyday activities in people living with HIV and other clinical populations is also necessary.

The researcher previously discussed the neuropsychological effects of HIV infection and the diagnosis of HAND in the post antiretroviral medication era. It is important to note that the evaluation of cognitive abilities is often confounded by critical psychological and psychopathological factors (Tedaldi et al., 2015). For instance, HIV infection has comorbidities with substance abuse (Anthony et al., 2007; Byrd et al., 2011; Rosenbloom et al., 2007) and psychiatric disorders, such as depression (Almeida et al., 2013; Nanni et al., 2015), that complicate cognitive deficits. Thus, the associations between psychiatric disorders and substance abuse deserve attention and will be conceptualized in the following sections.

The Effects of Psychopathology On HIV-associated Neurocognition

Major depressive disorder (MDD) is the most prevalent neuropsychiatric condition in individuals with HIV. Statistics suggest that approximately 45% of people living with HIV are also affected by depression (Almeida et al., 2013). Although there are no formal statistics about the incidence of depression in Latinos/as living with HIV, descriptive findings suggest that up to 50% of Latinos/as participating report depressive symptoms (Wohl et al., 2013). The diagnosis of depression in people living with HIV is difficult because it could be examined as a brain disorder associated with HIV or an adjustment reaction to the diagnosis of HIV infection. As such, it is possible that depression symptoms could be confounded, and confused, for cognitive deficits (Almeida et al., 2013). The relationship between cognitive deficits and depression related to HIV has been examined in some studies. For example, researchers reported that cognitive functioning measures were significantly lower in depressed patients compared to non-depressed controls (Braganca and Palha, 2011). Although this study was limited by a cross sectional and correlational design, it provided evidence suggesting group differences between depressed and non-depressed patients living with HIV with respect to cognition. Investigators have also indicated differences between young and older adults living with HIV in the relation between depressive symptoms and neurocognition (Shimizu et al., 2011). In this case, depressive symptoms predicted global neuropsychological impairments in younger adults, and psychomotor and global neuropsychological impairment in older adults. Taken together, the results suggest that cognitive impairment and depression are interrelated in the context of HIV infection and should be carefully controlled for in future studies in clinical and research settings. Furthermore, follow-up studies should consider being consistent in the measures of depression used.

Just as HIV infection could influence depressive symptoms, depression might increase the likelihood of HIV infection through poor decision-making and concentration (Neto et al., 2015; Hutton et al., 2004; Nanni et al., 2015). Nanni and colleagues (2015) posited that individuals who are suffering from depression may be more likely to engage in risky behaviors and make poor decisions that put them at risk for becoming infected with HIV. Then, if already-depressed individuals become infected with HIV, depressive symptoms could be exacerbated and quality of life can be further compromised. Given this complex relationship, especially in the clinical setting, practitioners need to consider psychological and social factors that might influence the patients' HIV neurocognitive profile and symptomatology.

According to recent statistics, 12% of Latinos/as newly diagnosed with HIV thought their infection was related to drug use, and up to 40% of Latinos/as living with HIV reported using controlled substances including alcohol and methamphetamines (CDC, 2015). Within a sample of 500 Latinos/as living with HIV 13% reported substance dependence, 12% reported marijuana use, and another 26% reported other illicit drug use (NSDUG, 2006). Nonetheless, Latinos/as living with HIV tend to use substances at similar rates than other ethnicities (Gonzalez et al., 2013). Alcohol abuse, and illicit substance use are comorbid conditions that are also related to, and confound, neurocognitive symptoms among people living with HIV (Chana et al., 2006; Gongvatana et al., 2014; Martin-Thormeyer and Paul, 2009; Rosenbloom et al., 2007). Substance use has been linked to medication nonadherence in people living with HIV that could result from neurocognitive dysfunction (Arnsten et al., 2002; Colfax and Shoptaw, 2005; Haltkis et al., 2005; Ingersoll, 2004; Sharpe et al., 2004). Although each independently could cause negative neurocognitive effects, concurrently, they produce a synergistic effect related to HIV pathogenesis by increasing viral load in the CNS and suppressing immune function (Anthony et

al., 2008). Some investigators have reported degenerative neurocognitive effects in HAND related to substance use (Chana et al., 2006; Durvasula et al., 2006; Gongvatana et al., 2014; Martin et al., 2003; Rothlind et al., 2005; Rippeth et al., 2004; Rosenbloom et al., 2007; Sassoon et al., 2007; Wisniewski et al., 2005), whereas others found no significant, or weaker, relationships (Byrd et al., 2011; Durvasula et al., 2006; Green et al., 2004). However, many of these research groups struggle to identify the source and onset of cognitive deficits because HIV infection, alcohol abuse, and illicit substances often occur concurrently. For instance, one research group reported no cognitive differences between HIV-positive and HIV-negative drug users, suggesting that substance abuse might account for cognitive impairments above and beyond HIV infection (Bono et al., 1996). Given the inconsistent findings, research in this area continues to be imperative, especially since concurrent substance use and HIV infection has vastly increased since the 1980s (Byrd et al., 2011).

Extant findings regarding the synergistic effects of concurrent HIV infection and substance use are inconclusive (Durvasula et al., 2006; Green et al., 2004; Rodriguez Salgado et al., 2006; Selnes et al., 1997). After reviewing several studies, it is evident that heterogeneity in study designs, measures, samples, and lack of covariates produce troubling confounds that may explain the conflicting findings (Byrd et al., 2011). Additionally, studies of single-drug-use abuse and HAND often do not control for past and present use of other substances (Leri et al., 2003; Staines et al., 2001). This is especially perplexing given that mono-drug abusers are almost nonexistent, especially when related to HIV (Byrd et al., 2011). In fact, mixed results have been reported by research groups in regards to polysubstance users, producing more evidence for the importance of further examining substance abuse in the HIV neurocognition context (Anthony et al., 2008; Martin et al., 2003).

cART and Neurocognition

Typical cART treatment consists of three antiretroviral medications in addition to other medications to attenuate side effects and or treat comorbid conditions that can range from a total of 4 to 12 pills a day on average (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2016). According to a longitudinal study reported by Hernandez-Arroyo and colleagues (2016), regimes remain complicated despite a decline in average number of pill intake by year 7.

Although researchers generally agree that antiretroviral medications assuage HIV-related symptoms, improve quality of life, and extend life (Hogg et al., 2008; Jacquet et al., 2013; Rosen et al., 2009), an optimal treatment for HAND-related effects has not been established. Overall, many investigators have reported that strict adherence to cART could lead to improvements in cognitive function associated with HIV disease. For example, even mono-ART treatments, which were routinely administered prior to the mid-1990s, were shown to be superior to placebo conditions in randomized controlled trials (Schmitt et al., 1988; Sidtis et al., 1993). In one particular trial, improvements in attention, memory and motor functioning were found in the treatment group compared to placebo (Schmitt et al., 1988). Similar results were found when this medication was examined in patients with HAD (Sidtis et al., 1993), although the results tend to be ephemeral in this clinical group (Tozzi et al., 1993). Nonetheless, the effect sizes and group differences vary by study probably due to sample sizes, demographic differences, measure variety, and medication type.

Although mono-ART revealed improvements in neurocognition, it is well established in the HIV literature and clinical practice that cART is the standard treatment for HIV and substantially more effective than single medications or placebos (Ferrando et al, 1998). To that end, several researchers have concluded that some patients who follow cART regimes show

improvements on neuropsychological tests of attention, concentration, learning, memory, and psychomotor speed compared to patients not taking cART (Price et al., 1999; Sacktor et al., 1999; Tozzi et al., 1999). This finding held up in single session and longitudinal studies of up to 5 years (Cole, 2007; Heaton et al., 2015; Ferrando et al. 2003; Suarez et al., 2001). Furthermore, some research groups have identified medication regimes that are more efficacious at improving neurocognition (discussed further below; Clifford, 2008; Letendre et al., 2008; McArthur et al., 2005), although more work is needed to identify potential mechanisms. In general, longitudinal findings suggest that psychomotor speed is most improved when adhering to cART, compared to executive function and learning and memory, suggesting that subcortical structures are sensitive to HIV-related pathologies and subsequent treatment (Ferrando et al., 2003). However, executive function and learning and memory performance showed improvement following treatment in other trials (Ghate et al., 2015; Price et al., 1999; Sacktor et al., 1999; Tozzi et al., 1999; Zhuang et al., 2017).

Researchers have also examined CNS biomarkers that may be indicative of cognitive improvement related to cART. For example, investigators have indicated that HIV RNA decline in CSF is suggestive of cognitive improvement (Marra et al., 2003) whereas subsequent studies have not found an association between HIV RNA decline and cognitive improvement (Cysique et al., 2006; Letendre et al., 2004; Robertson et al., 2007). More recent clinical trials have been completed and investigators reported that cART was related to higher brain ratios of N-acetylaspartate-to-creatine (NAA/CR), a biochemical marker of cellular energy that predicts neuronal density and thus brain and cognitive integrity (Winston et al., 2010). The aforementioned brain biometric evidence suggest that levels of CNS biomarkers could be indicative of cART adherence and medication effectiveness in treating structural brain

abnormalities and cognition related to HIV, although more research is necessary to resolve varying findings.

Despite the obvious advantages of cART, it appears that cART alone is insufficient to completely reverse neurocognitive impairment related to HAND (Tozzi et al., 2007). For instance, as many as 40% of cognitively impaired HAND patients remained impaired despite three years or more of cART adherence in one study (Tozzi et al., 2001). Other research groups have reported that the incidence of HIV dementia and other neuropsychological impairment did not differ across groups who were examined pre and post cART (Sacktor et al., 2002) and subsequently the prevalence of neurocognitive impairment was not significantly different among subjects who were examined in the pre or post cART eras (Cysique et al., 2004). The aforementioned investigators indicated that even though cART is certainly useful, cognitive deficits might not be fully improved by medications. Although these researchers did not investigate the mechanisms behind these effects, the findings may be confounded by total time receiving treatment at the time of the study and overall length of infection before treatment commenced. However, authors from a different clinical trial have reported improvements in psychomotor and processing speed tests in treatment groups following cART, suggesting that treatment could be helpful in improving cognitive impairment without completely reversing previously met diagnostic criteria for HAND (Ferrando et al., 2003; Suarez et al., 2001).

Biomarkers have been investigated in conjunction with cognitive deficits in HIV treatment groups. In one study, cART led to improvements in some patients while a disappointing 30% continued to show cognitive deterioration (Cysique et al., 2006). This study revealed that cognitive impairments were related to lower CD4 cell counts and past HIV-related brain disorders. Other investigators concluded that patients with cognitive dysfunction who have

never participated in cART did not improve after being treated despite HIV suppression in CNS biomarkers such as CSF and plasma (Carvalho et al., 2006). Some patients appear to suffer irreversible damage that may be partly due to neural injury despite adherence to cART. Thus, even though several researchers reported that cART supported changes in biomarkers, such as suppression of plasma and CSF, HIV may continue to replicate within the CNS at detectable levels indicating drug resistance (Canestri et al., 2010). Taken together, these investigations provide more evidence for the varying effects of cART.

Since the introduction of cART in 1996, many medications have become available that have been shown to be helpful in suppressing HIV viral load and improving HIV symptoms. In regards to brain function, however, it appears that certain ART medications are more efficacious at treating detectable viral loads in the CNS (Marra et al., 2003; Polis et al., 2003) and improving cognition (Cysique et al., 2009; Cysique et al., 2011). ART medications are now awarded CNS-penetration-effectiveness (CPE) ratings that estimate a medication's level of effect on the CNS (Clifford, 2008; Letendre et al., 2008; McArthur et al., 2005). This ranking system was developed after researching the treatment relationships among CSF viral levels, blood viral load reduction, and subsequent cognition (Clifford, 2008; Letendre et al., 2008). Findings suggest that medications with higher CPE more adequately target CNS and produce greater reductions in CSF HIV RNA levels (Letendre et al., 2008; Marra et al., 2009). According to a report by Letendre and colleagues (2010), Zidovudine, Nevirapine, and Indinavir have the highest CPE rankings with scores of 4. However, the most prescribed medications are Tenofovir (CPE =1), Emtricitabine (CPE = 3), Efavirenz (CPE =3), and Atazanavir (CPE =2; Glesby et al., 2014). Nonetheless, it is necessary to take into account that, increases in CPE and reductions in HIV biomarkers are not always associated with improvements on neuropsychological tests (Marra et

al., 2009) or even survival (Mcmanus et al., 2011). Several authors have reported discordant findings in regards to neuropsychological improvements following intake of medications with higher CPE and reduction of HIV biomarkers (Letendre et al., 2008; Marra et al., 2009). One study found the opposite; patients taking medications with lower CPE rankings performed better on neuropsychological tests after treatment compared to patients who took medications with higher CPE rankings (Marra et al., 2009). Studies are currently underway to disentangle the mechanisms responsible for these non-uniform effects.

In general, cART is typically effective in attenuating neuropsychological deficits on standardized measures even if the longevity of improvement varies (Cole, 2007; Heaton et al., 2015; Ferrando et al. 2003; Suarez et al., 2001). Additionally, neuropsychological improvement could correspond with CNS and PNS biometric measures of viral suppression and detectable loads although the results are mixed (Cysique et al., 2006; Letendre et al., 2004; Marra et al., 2003; Robertson et al., 2007). In the following section, the researcher will discuss potential barriers to medication adherence that have been identified in patients living with HIV.

Barriers to Medication Adherence

Medication adherence is a critical component of health and health care. The United States, along with other developing nations, reportedly has low levels of adherence to medication regimes. In fact, investigators have estimated that 20-80 percent of patients do not adhere to medication regimens (WHO, 2003; DiMatteo, 2004; Kardas et al., 2013; NCPIE, 2007) with Latinos/as being less like to adhere compared to non-Hispanic White patients in the context of HIV treatment (Silverberg et al., 2009; Sullivan et al., 2007). The large variance in reported adherence rates results from methodological differences, definitions, and populations studied. In

essence, how adherence is defined, evaluated, measured, and which populations are enrolled significantly influences adherence rates.

Adherence to cART in HIV infection is the most important contributor to viral suppression and a key factor in the maintenance of health and quality of life in patients living with HIV (Bangsberg et al., 2001). In fact, patients who disrupt cART are at risk of developing viral resistance (Bangsberg et al., 2007; Genberg et al., 2012). Investigators have shown that patients with HIV struggle to maintain adherence necessary to effectively treat HIV (Mills et al., 2006). Since HIV treatment requires adherence throughout the life of the patient, adherence is a long-term challenge for most patients. As a result, it is important to understand potential barriers to medication adherence to cART in people living with HIV.

In the following paragraphs, important barriers to medication adherence that have been identified in the HIV patient population will be discussed. The treatment of HIV is a multi-layered approach that could encompass social, medical, and psychological variables. Not only does HIV infection induce physiological changes (G Elfaki, 2014), but it also has social effects such as stigma and social support that could affect a person's experience (Earnshaw et al., 2015; Johnson et al., 2012; Katz et al., 2013; Lehavot et al., 2011). Similarly, psychological consequences such as depression and substance use could result from the physical and social experiences (Colfax and Shoptaw, 2005; Haltkis et al., 2005; Lowther et al., 2014; Nanni et al., 2015; Simoni et al., 2011). Unfortunately, all experiences related to HIV are not conducive to treatment adherence and positive treatment outcomes.

Depression in people living with HIV, including Latinos/as, is the most common neuropsychiatric complication that limits quality of life and has been identified as a primary barrier to medication adherence (Longoria et al., 2007; Lowther et al., 2014). Some evidence

indicates that being diagnosed with HIV leads to social and psychological changes that in turn could lead to depressive symptoms (Lowther et al., 2014; Phillips et al., 2004; Schuster et al., 2012). Still others note that depression in people who are HIV-negative could lead to risky behaviors that increase the risk of becoming infected with HIV (De Santis et al., 2008; Nanni et al., 2015). Nonetheless, depression could exacerbate physical symptoms of HIV (fatigue, muscle aches, rash, fever, etc) and impair treatment management and medication adherence (Leserman, 2003; Leserman et al., 2008; Simoni et al., 2011). Whether depressive symptoms manifest as cognitive difficulties that impair medication management or whether depression results in a lack of motivation that prevents patients from adhering to their pills, investigators have concluded that depression symptoms are significantly related to worse HIV treatment adherence (Carrico et al., 2011; Summari-de Boer et al., 2012). However, other investigators have reported weaker relationships between depressive symptoms and medication adherence, especially when controlling for demographic variables (Aikens et al., 2005; Duran et al., 2001; Gifford et al., 2000; Stone et al., 2001). Treating depression could lead to better medication adherence and viral suppression, indicating that the detrimental contributions of depression to HIV symptoms and treatment, especially medication adherence, are treatable and possibly completely reversible (Moosa & Jeenah, 2012; Tsai et al., 2010; Yun et al., 2005).

Beliefs about medications is another important contributor to medication nonadherence in individuals taking cART (Gonzalez et al., 2007). For example, believing that medications will be helpful is positively related to high rates of medication adherence (Bogart et al., 2016; Haro-Marques et al., 2015; Kalichman et al., 2016; Kalichman et al., 2015; Kalichman et al., 2015b). The perceived impact, or the patient's perception of treatment efficacy and importance, plays a similar role especially when treatment does not produce desired effects (Horne et al., 2004). In a

similar vein, medication knowledge and experiences with side effects are important predictors of medication adherence because individuals who experience more severe side effects, even when the treatment is effective, might be less likely to take their medications if they actually feel worse after ingesting them (Melbourne et al., 1998; Mills et al., 2006.). For example, experiencing fewer symptoms is associated with better adherence (Ammassari et al., 2001; Holzemer et al., 1999; Wagner, 2002). These findings suggest that patient perceptions about medications that are influenced by their experiences with symptoms are important in determining beliefs about medications and their perceived efficacy. Even if cART is successful in decreasing viral load, a patient may perceive the medication as unhelpful if it does not reduce uncomfortable symptoms related to HIV. Thus, beliefs about medications related to HIV symptomatology and personal experiences are influential contributors to HIV medication adherence that could also serve as a barrier.

Although regimen complexity in cART has decreased since its beginnings in 1996, a high number of prescriptions continues to be a barrier in HIV treatment. Generally, as the number of prescription medications increase, the more difficult it is to track and manage ingestion, especially in populations who might suffer from cognitive impairment (Hughes, 2004; Fogarty et al., 2002; Mills et al., 2006). This relationship becomes even more confounded as the number of diseases and conditions that require medication increases among people who are HIV-positive (Balkrishnan, 1998; Fogarty et al., 2002; Hughes, 2004). Given this important barrier, the relationship between medication adherence and number of prescriptions has been studied. In general, most findings have concluded that a greater number of prescriptions is related to poorer adherence (Mills et al., 2006; Saini et al., 2009). For example, as the number of daily doses increased participants were less likely to adhere. Another researcher who studied older adults,

however, suggested that higher complexity actually leads to better medication adherence (Lau et al., 1996). Researchers attribute these findings to practice and organizational effects, as patients with many prescriptions might have more experience because they have been taking medications for longer periods of times. Still, other researchers have indicated opposite or null results for this relationship, although findings may have been confounded by demographic, methodological, or statistical variables (Vik et al., 2004). For example, some investigators have reported that increased nonadherence when number of prescriptions increased was moderated by the increasing cost of medications (Vik et al., 2004). Given this inconclusive relationship between number of prescriptions and medication adherence more work is required in this area.

Substance use is a highly prevalent comorbid condition among people living with HIV, as previously discussed (McGowan et al., 2011; Skeer et al., 2011; Treisman et al., 2007). Among its many complications, substance abuse is related to poor medication adherence among people living with HIV and is thus considered an important barrier (Arsten et al., 2002; Hinken et al., 2004; Tucker et al., 2004). Recently, however, some null findings were summarized in a meta-analysis in which researchers reported that in general that drug users and non-users had similar adherence rates (Malta et al., 2010). Nonetheless, there is individual evidence that alcohol, methamphetamines, cocaine, tobacco, and heroin use are related to medication nonadherence in people living with HIV (Arsten et al., 2002; Colfax and Shoptaw, 2005; Haltkis et al., 2005; Ingersoll, 2004; Sharpe et al., 2004). Neurocognitive deficits and psychopathology have been cited as possible mechanism in which substance use might negatively influence adherence behaviors (Chang et al., 2002; Volkow et al., 2001). For example, cocaine and methamphetamine use has been especially suggested to be related to cognitive impairment that could affect medication adherence (Gonzalez et al., 2004; Hinkin et al., 2007; Levine et al., 2006). Others

posit that medication nonadherence may be due to the non-consistent and chaotic social lifestyles substance users might live that impair dietary restrictions and medication management (Tucker et al., 2004). Substance use has been somewhat consistently reported as a barrier to medication adherence in people living with HIV and should be considered in HIV research.

In conclusion, researchers have reported that depression (Langebeek et al., 2014; Summari-de Boer et al., 2012), beliefs about medications (Gonzalez et al., 2007), number of prescription medications (Hughes, 2004), and substance use (Arnsten et al., 2002; Colfax and Shoptaw, 2005; Haltkis et al., 2005; Ingersoll, 2004; Sharpe et al., 2004) are key variables that contribute to differential rates of medication adherence in clinical populations.

Neurocognition, Medication Management, and Medication Adherence

Researchers have determined that regimen complexity and larger number of prescriptions could pose challenges to medication adherence across various medical conditions, including HIV/AIDS (Hughes, 2004; Fogarty et al., 2002; Mills et al., 2006; Saini et al., 2009). The ability to properly execute prescribed medication regimens is conceptualized as medication management, and deficits in this skill are a predictor of unintentional medication nonadherence (Frain et al., 2014; Patton et al., 2012). Neuropsychology researchers have reported that effective medication management requires decision-making, organization, and prospective memory which necessitate intact cognitive processes under the executive function, language, and learning and memory domains (Brown & Park, 2003; Thames et al., 2011; Waldrop-Valverde et al., 2010). Given that HIV infection results in neurocognitive deficits that could affect activities of daily living (Woods et al., 2007; Woods et al., 2009), medication management impairments in laboratory measures resulting from cognitive dysfunction have been examined in people living

with HIV (Albert et al., 1999; Albert et al., 2003; Thames et al., 2011; Thames et al., 2013). Researchers have reported that deficits in neurocognition predict poor medication management in individuals living with HIV and other clinical populations (Depp et al., 2008; Patton et al., 2012; Patterson et al., 2002; Pirogovsky et al., 2012). Specifically, deficits in executive function, learning and memory, and processing speed domains have been linked to challenges with medication management.

Medication management ability has been evaluated using laboratory measures that require participants to acquire a new medication regime and simulate medication intake with a researcher. Two well-known laboratory measures are the Medication Management Ability Assessment (MMAA) and Medication Management Test-Revised (MMT-R) which simulate a consultation and include a role-play in which participants are asked to organize medication as they were to ingest them through the day (Albert et al., 1999; Albert et al., 2003; Depp et al., 2008; Frain et al., 2014; Patterson et al., 2002; Patton et al., 2012; Thames et al., 2011). Both medication management tasks have been investigated in relation to neuropsychological measures and demonstrate good concurrent and predictive validity (Depp et al., 2008; Patterson et al., 2002; Patton et al., 2012). Researchers have reported that, although varied, the results generally suggest that executive function, psychomotor speed, and learning and memory domains are related to components of medication management ability as measured by MMAA and MMT-R. In some instances, investigators have indicated that medication management laboratory measures significantly predicted real medication adherence in clinical populations, whereas others reported no significant associations (Albert et al., 1999; Patterson et al., 2002; Patton et al., 2012; Thames et al., 2011). Nonetheless, these relationships are often confounded by measures of medication

adherence as they vary among self-report, investigator ratings, pharmacy refill records, and electronic pill dispenser measurements.

Although the findings between medication management and adherence are inconsistent, it is important to note that both are strongly related to cognitive abilities that have been shown to be impaired by HIV (Albert et al., 1999; Albert et al., 2003; Depp et al., 2008; Frain et al., 2014; Patton et al., 2012; Thames et al., 2011). In previous sections, the researcher identified several neurocognitive impairments that result from HIV infection; many that are important for medication management and adherence. Medication adherence and neuropsychological functioning are interactive variables in that cognitive dysfunction could lead to attenuated medication adherence that allows HIV replication in the CNS, which in turn could lead to more neurocognitive deficits. For example, investigators have reported that better global neurocognitive functioning predicts superior medication adherence in people living with HIV (Andrade et al., 2012). Specifically, neuropsychology investigators have indicated that, similarly to medication management, intact executive function, memory, language, psychomotor and processing speed domains predict better medication adherence in people living with HIV (Andrade et al., 2012; Woods et al., 2008; Woods et al., 2009). Generally, investigators also suggest that neurocognitive domains are required for successful medication management (Andrade et al., 2012; Ettenhofer et al., 2009; Ettenhofer et al., 2010). Thus, the relationships among medication management laboratory measures, medication adherence, and neurocognition are interactive in that proper management is required for adherent behavior, yet neurocognitive deficits could interrupt proper management and adherence that could in turn produce more neurocognitive deficits. These relationships have not been examined in monolingual Spanish-speaking Latinos/as living with HIV.

Original Study

In the first section, the investigator summarized the effects of HIV in the CNS from the cellular to the cognitive level. Researchers have determined that HIV has deleterious effects on structural and function brain integrity (Holt et al., 2012). These structural and functional brain alterations cause cognitive deficits in patients living with HIV that affect their ability to manage medications on laboratory measures (Andrade et al., 2012; Albert et al., 2003; Albert et al., 1999; Frain et al., 2014; Patton et al., 2012; Thames et al., 2011; Thames et al., 2013; Woods et al., 2009). In turn, impairments in medication management laboratory measures could inform challenges in cART medication adherence that compromise health status and cognition (Albert et al., 2003; Albert et al., 1999; Patton et al., 2012). Given that Latinos with HIV are more likely to show cognitive deficits compared to Caucasian HIV-positive patients (Marguine et al., 2018), the original aim of the study was to examine the relationships among neurocognition, medication management, and medication adherence, in a Latino/a sample living with HIV. Although researchers have investigated how sociocultural and demographic variables affect the HIV experience (De Santis et al., 2012) and reported that medication adherence rates are compromised in ethnic minorities (Gantz et al., 2014; Oh et al., 2009), especially Latino/a patients living with HIV (Silverberg et al., 2009; Sullivan et al., 2007), the neurocognitive effects of HIV on activities of daily living have not been examined in monolingual Spanish-speaking Latinos/as living with HIV. Previously, researchers have determined that cognitive abilities were superior in English-speaking Non-Hispanic White individuals living with HIV compared to English-speaking Hispanic participants (Mindt et al., 2014). Other groups have suggested that HAND might also be more prevalent in Hispanic populations (Rivera Mindt et al., 2008; Wojna et al., 2006). The goal of this study, then, is to examine the relationships among

neuropsychological measures, laboratory measures of medication management ability, cART adherence as measured by self-report and pharmacy refill records, and biometric information in monolingual Spanish-speaking Latinos/as living with HIV.

Case-Study Evolution

The researcher experienced difficulties with recruitment and collecting valid and complete data from patients who enrolled in the study. In later chapters, he will describe the efforts that were made to improve recruitment and data collection. However, the dissertation evolved in focus to examine the data had collected using a case study framework (Berk, 2000; Bronfenbrenner, 1977, 1979). The researcher will apply the Bronfenbrenner Ecological Systems model to guide a qualitative case study application of the problems with the original design.

Bronfenbrenner's Ecological Systems Theory

Bronfenbrenner's Ecological systems theory characterizes five environmental systems in which an individual interacts and aids in examining individual's relationships within extended communities and wider society (Bronfenbrenner, 1977, 1979). As seen on *Figure 4*, this model frameworks five ecological systems. The microsystem refers to organization, institutions, and groups that most directly impact the patient's experience, such as their interaction with me and the required tasks during their participation in the research study and their experience with healthcare providers at the SSC. The mesosystem describes the interconnections between the microsystems in which the patient inhabits, such as the relationship between the university carrying out the research

study and the SSC. The exosystem characterizes the association between a patient's immediate environment and social setting in which the patient does not have an active role, such as administration at a university or a medical setting. The macrosystem refers to the cultural, socioeconomic, hereditary, biological, educational, racial, and political contexts in which the patient is embedded, such as health care inequalities, oppressive politics, racism, social stratification inequalities, and economic inequalities. The chronosystem is composed of chronological events and transitions over the course of the patient's life that affect their experiences. The researcher will take an analytical approach to the data to answer questions within the framework of the microsystem, mesosystem, exosystem, and the macrosystem.

Original Specific Aims and Hypotheses

Specific Aims

1. Determine if executive function and memory composite scores have predictive validity with measures of medication management and medication adherence in monolingual Spanish-speaking Latinos living with HIV.
2. Determine if executive function and memory composite scores, measures of medication management, and medication adherence have a predictive validity with biometric measures of CD4 cell count and viral load among monolingual Spanish-speaking Latinos living with HIV.

Hypotheses

1. Better executive function and memory composite scores will significantly predict better MMAA scores, when controlling for depression and substance use.
2. Better executive function and memory composite scores will significantly predict better medication adherence scores, as measured by pharmacy refill records, when controlling for depression and substance use.
3. Better MMAA scores will significantly predict better medication adherence scores, as measured by pharmacy refill records, when controlling for depression and substance use.
4. Better executive function and memory composite scores, MMAA, and medication adherence scores will significantly predict higher CD4 cell count and lower viral loads.
5. The relationship between medication management ability and medication adherence measures/biometric measures will be mediated by executive function/memory composite scores.

Chapter 2 - Method

Participants

As described in *Table 1*, twenty-three (23) patients called to be screened to participate in the study. Eligible participants who were enrolled included 17 monolingual Spanish-speaking patients, of Mexican and Puerto Rican descent and who were diagnosed with HIV and who had been taking cART medications for at least 1-month (31 days). These criteria have been used in a previous study involving a similar patient population (Andrade et al., 2012). Participants were from low-income Latino communities in the greater Milwaukee area, between the ages of 29-49 years and recruited from the Sixteenth Street HIV Clinic in Milwaukee, a low-fee clinic on Milwaukee's predominantly Mexican South side. Patients over the age of 50 were not allowed to participate in order to avoid confounding the effects of HIV infection with those of aging (DeVaughn et al., 2015). All patients received \$30 for participation. Study sessions lasted no longer than two hours. Patients with an existing history of brain injuries and/or strokes were excluded from participating. Patients with an existing history of substance abuse were not excluded because the evidence is inconsistent with respect to whether substance abuse substantially affects neurocognition in the context of HIV and cART (Byrd et al., 2011). Additionally, given the comorbidity between psychological disorders and HIV, patients reporting depressive and anxiety disorders were not excluded. However, patients who reported other psychological or brain disorders that could interfere with testing (bipolar disorders; schizophrenia; obsessive-compulsive disorders; eating disorders; autism; attention-deficit/hyperactivity disorder [ADHD]; learning disabilities; intellectual disabilities) were excluded from participating.

Recruitment commenced on October 12, 2016 and concluded on December 8, 2017. During this time, 17 participants were enrolled and after conducting an analysis to determine completion and validity of the collected data, only seven participants had complete data. Participants whose data were considered “complete” answered all interview and survey questions and had valid data points for all neuropsychological and computerized tests. Of the 10 participants whose data were considered incomplete, four reported ingesting a mood-altering substance (marijuana, narcotics, or sedatives) the day of the study session, two reported severe psychiatric symptoms that could confound performance, and four patients had difficulties understanding task instructions and reported possible learning difficulties in academics. For the purposes of comparing the groups, participants were separated into those with complete data and those with incomplete data (see *Table 2*). Wilcoxon-Mann Whitney Tests revealed there were no significant differences in demographics between groups ($p > .05$).

Neuropsychological Measures and Clinical Surveys

Brief Standardized Neuropsychological Battery

When deciding on the specific neuropsychological battery to use for this study, the researcher reviewed the literature and evaluated similar studies conducted within similar participant demographic groups. At the time of the conception of this study, few studies were published that had examined medication adherence in Spanish-speaking monolinguals living with HIV. The study that was used to develop our design (Andrade et al., 2012) utilized tests that were originally developed in English and were translated to Spanish and that had some specific norms that were developed with Latinos (Cherner et al., 2007). It is important to note that Spanish clinical neuropsychology practice occurs in

few clinics in the United States, and most utilize norms from non-Latino populations to make an interpretation. Thus, there were no published studies available to assist in the best practices to develop a usable neuropsychological battery of tests, although there is significant evidence that demographic variables (Pineda et al., 2000) and level of acculturation affect neuropsychological performance (Byrd et al., 2005). However, we did have awareness of problems with certain tests and difficulties recruiting Latinos for research in general. For example, De La Rosa and colleagues (2012) reported difficulties in recruiting Hispanic/Latino, monolingual Spanish-speaking patients living with HIV for studies that require lengthy time commitments. The authors reported that difficulties in recruitment were due to insufficient economic incentives, transportation challenges, or lack of child care (De La Rosa et al., 2012). Additionally, the diversity in Spanish dialects and formal education could confound performance on tasks that rely heavily on language abilities or that were significantly related to total years of education and IQ scores. Therefore, standardized measures used in clinical and non-clinical populations that were validated in Spanish-speaking samples or that do not rely heavily on language abilities were selected for the test battery. The array of measures tapped into learning and memory, processing speed, and executive functioning. Only tests that had been previously used in Spanish-speaking samples or that did not rely heavily on language abilities were used. When this original dissertation was proposed there were no published studies with norms and discussion of tests to use with this population. Since then, several studies have been published (Arago-Lasprilla et al., 2015; Guerrero-Berroa et al., 2016; Vivas et al, 2017). The battery included the following neuropsychological measures:

The Hopkins Verbal Learning Test-Revised (HVLTR) is a measure of verbal learning memory used in research and clinical settings in which participants are read a serial list of Spanish words three times and then tested on their delayed recall and recognition memory of the words (Brandt & Benedict, 2001). The original test is a standardized measure of learning and memory that has been found to be confounded and limited by education and that is significantly related to other measures of processing speed, memory, working memory, and executive functions in a pilot study that was conducted in our laboratory with young and older typically-developing adults. Initially, early research suggested that only age was a significant confounding variable that influenced performance (Brandt & Benedict, 2001). However, a detailed analysis in Spanish-speaking adults determined that there was a high rate of misclassification of neurologically intact adults as having neurological dysfunction. Therefore, investigators developed formulas to correct these norms and provide validated scores for monolingual Spanish-speaking individuals (Cherner et al., 2007). Reliability analysis for our sample yielded a $\alpha=.61$ which is in the questionable range and thus provides evidence for poor reliability and internal consistency. This is probably due to the small sample size and wide margin variability in age.

The Brief Visuospatial Memory Test-Revised (BVMT) is a measure of visuospatial memory in which participants are shown a sheet with six figures three different times and then are tested on their delayed recall and recognition memory of the shapes and their spatial locations (Benedict, 1997). Like the HVLTR, this test is an established standardized measure of learning and memory that was found to be confounded by education and that is significantly related to measures of working

memory, processing speed, and executive functioning as shown in our pilot study with healthy, typically-developing young and older adults. However, this test, similarly to the HVLТ discussed above, was yielding a higher percentage of misclassification of neurologically intact patients as having brain dysfunction. Therefore, corrected norms were also offered for monolingual Spanish-speaking individuals (Cherner et al., 2007). The immediate and delayed recall portions of BVMT-R are highly dependent on psychomotor ability given the drawing/constructing requirement of the figures (Benedict, 1997). For the purpose of this study, the researcher only utilized the delayed recall component. Reliability analysis for our sample yielded a $\alpha=.67$ which is in the questionable range and thus provides evidence for poor reliability and internal consistency. Again, this is a byproduct of the sample from which the data were collected rather than the measure itself.

Computerized Tasks

Berg's Card Sorting Test (BCST)

This computerized task that tapped into executive functioning abilities was adapted from the physical version of the WCST, shows good internal consistency with the computerized version of WCST in research and clinical practice, and has been validated with healthy, typically-developing adult young and older populations (Fox et al., 2013; Heaton, 1981; Mueller & Piper, 2014). This task required higher order thinking abilities including abstract concept formation, set-shifting, and inhibitory control (Heaton, 1981). In this task, participants were asked to match card appearing one at a time at the bottom of the screen with one of four key cards appearing at the top of the

screen (*Figure 1*). After each sort, participants were informed whether they are correct or incorrect. Sorting rules could not be explained in advance and participants had to try their best to make correct choices based on the feedback provided after each response. After a certain number of correct trials, the matching rule was switched without notice by the program. When this shift occurred, the participant was to determine the new rule through trial and error. This process was repeated until 6 categories had been successfully completed or until all of the cards had been administered. Performance on a different version of this task was not affected by language of administration (English or Spanish) in Hispanic American bilingual adults (Gasquoine et al., 2007).

Transverse Patterning Task (TPT)

This computerized task was adapted from previous experiments with human participants (Carlozzi and Thomas, 2008) that have shown that the construct measured depends on the hippocampus (Rickard et al., 2006) and therefore has not been validated for clinical and standardized use. Participants were presented with two distinct visual stimuli (*Figure 2*) and were asked to pick one at random by pressing a computer key. After key press the computer screen informed the participant if the response was correct or wrong, and participants were instructed to keep choosing the correct picture from the pair. The task was presented in a stepwise approach that incorporated 3 stages. In stage 1, participants were presented with (A+, B-). In stage 2, participants were shown (A+, B-) and introduced to (B+, C-). In stage 3, participants were shown (A+, B-), (B+, C-), and introduced to (C+, A-).

Participants chose stimuli by pressing one of two designated keys that corresponded to the left or the right side of the pair. Correct responses were followed by a presentation of the word 'CORRECT' in the center of the computer screen displayed together with a unique tone for 1 second. Incorrect responses were followed by the word 'WRONG' presented in the center of the computer screen displayed together with a unique tone for 1 second. The task continued until participants reached a criterion of 14 correct responses out of 15 consecutive trials in each phase. However, the task was discontinued if the maximum of 500 trials is achieved.

Reversal Task (RT)

This computerized task was adapted from previous experiments with animals in which contingencies are learned and then reversed (Chang et al., 2014; Murray et al., 2007). Although this task has not been validated on human samples, similar tasks have been shown to depend on the frontal cortex, a brain region associated with various executive functions (Murray et al., 2007). Participants were presented with two distinct visual stimuli (*Figure 3*) and were asked to pick one at random by pressing a computer key. After a key press the computer informed the participant if the response was correct or wrong. The task was presented in a stepwise approach that incorporated 6 stages. In stage 1, participants were presented with (A+, B-). In stage 2, participants were presented with (A+, B-) and introduced to (C+, D-). In stage 3, participants were presented with (A+, B-), (C+, D-), and introduced to (E+, F-). In stage 4, the contingencies were reversed with (E-, F+). In stage 5, participants were presented with (E-, F+) and (C-, D+). In stage 6, participants were presented with (E-, F+), (C-, D+), and (A-, B+).

During each stage, participants chose a stimulus by pressing one of two designated keys that corresponded to the left or the right side of the pair. Correct responses were followed by a presentation of the word ‘CORRECT’ in the center of the computer screen displayed together with a unique tone for 1 second. Incorrect responses were followed by the word ‘WRONG’ presented in the center of the computer screen displayed together with a unique tone for 1 second. The task continued until participants reached a criterion of 14 correct responses out of 15 consecutive trials in each phase. However, the task was discontinued if the maximum of 500 trials was achieved, consistent with the transverse patterning task.

Medication Management, Medication Adherence, and Biometric Measures

Medication Management Ability Assessment (MMAA)

This task was originally designed by researchers to provide a realistic simulation of medication management (Patterson et al., 2002). Participants are asked to pretend they are visiting a doctor where they are given instructions about taking four prescription medications to treat a cold, emulating a realistic pharmaceutical consultation. After a 45-minute delay, participants are asked to role-play how (with or without food) and when (before breakfast, after lunch, dinner, etc.) they would take medications, simulating a realistic medication management situation. Participants handed the researcher the pills they would “ingest” as they progressed throughout the day. The researcher wrote down the medicine name, number of pills and times of “ingestion,” but did not provide any feedback or assistance in completing the medication management assessment. This task has been shown to have good test-retest reliability and predictive validity (Patterson et

al., 2002). Notably, this task been previously used in Spanish-speaking adults with schizophrenia and shows convergent validity as performance did not differ in age and education matched English-speaking adults with schizophrenia (Bengoetxea et al., 2014).

Psychosocial Screening Interview and Clinical Questionnaires

Prior to enrolling in the study, interested patients underwent a brief psychosocial screening interview to gain information about psychological and substance use history. They were asked several questions about their medication adherence, age, gender, sexual orientation, immigration status and race/ethnicity. Then, they were asked about lifetime mental health diagnoses such as depressive disorders, bipolar disorders, schizophrenia, anxiety disorders, obsessive compulsive disorders and history of learning and/or academic challenges. Participants also answered questions about previous head or brain injuries or an existing history of brain disorders. Next, they were asked to report any medications they are currently taking that are not presently in their Sixteenth Street clinic file. Participants would be excluded if they reported learning disabilities and hallucinations.

If patients passed the screening procedure, during the testing session they completed the Spanish Addiction Severity Index (S-ASI) interview where patients were assessed for current and lifetime alcohol abuse and drug use (marijuana, cocaine, crack, heroin, methamphetamine, painkiller; Butler et al., 2009). Participants were asked to indicate how often they used illicit drugs to get high or change how they feel. Participants were asked if they ingested any substance today and were dismissed if currently under the influence of such drugs. Participants were asked to fill out a self-report measure of

depression. All participants completed the Center for Epidemiologic Studies Depression Scale (CES-D), Spanish version. The scale is well known and remains as one of the most widely used instruments in the field of psychiatric epidemiology (Naughton and Wiklund, 1993). The Spanish version has been previously validated and determined to be a valid instrument to detect depression in research settings, especially given the dearth of depression assessment instruments in Spanish (Ruiz-Grosso et al., 2012).

Although patients were asked information about their psychological and psychiatric history, due to time constraints and the scope of the study, the researcher did not include a structured clinical interview to diagnose psychopathology as detailed by the Diagnostic and Statistical Manual-5 (DSM 5). Thus, he relied on self-report.

Patients completed the Antiretroviral Medication Adherence Survey, a self-report measure of medication adherence to their prescribed HIV medications (Mathews et al., 2008). Items in this measure ask patients to list the medications they are currently taking and indicate the number of doses missed for each medication. Questions in this measure have been shown to significantly predict medication non-adherence in patients with HIV (Duggan et al., 2009).

Statistical Analyses

Wilcoxon-Mann Whitney Tests were performed to examine group differences on demographic variables, such as age, years of education, income, years taking HIV medication, and years since HIV diagnosis, and revealed no significant differences ($p > .05$).

Qualitative Analysis

The researcher experienced difficulties with recruitment and collecting valid and complete data from patients who enrolled in the study and will describe the efforts that he made to increase patient awareness of the study and enrollment numbers. However, after a one-year recruitment period and with the support of the dissertation committee and advisor, the researcher changed the focus of the dissertation to examine the data that were collected using a case study analysis (Berk, 2000; Bronfenbrenner, 1977, 1979). The researcher used Bronfenbrenner Ecological Systems model to guide the qualitative case study exploration of the problems with recruitment, difficulties collecting valid and complete data from patients who did enroll and detail the steps the investigator took to trouble shoot study difficulties during its active period with the pool of participants as the unit of interpretation and exploration. Data were triangulated from different perspectives and two case study types were used to frame the study (Baxter and Jack, 2008). The first type was an explanatory case study design, as an aim of the researcher was to seek an explanation for a complex phenomenon that was unable to be captured quantitatively (Joia, 2002; Yin, 2003). The second is an exploratory case design in which a process or intervention is being evaluated, but it does not have a single set outcome (Lotzkar and Bottorff, 2001; Yin, 2003). Firstly, the researcher analyzed the quantitative data that included demographics, patient HIV variables, progression of disease and complications, neuropsychological data, and results from self-report measures. Then, the investigator conceptualized qualitative information that was gathered through the screening procedure, interviews, brief conversations, and final thoughts during the study session. Data from personal observations at recruitment events and meetings with case managers

and the clinic director were obtained and utilized to understand the context in which the patients interact. Finally, the investigator compared current findings to the literature in barriers to research recruitment in Spanish-speakers, and other variables that affect participation, recruitment, and acquisition of valid data. This was an attempt to determine if the findings were consistent with previous research of Spanish-speaking recruitment and provide suggestions for future area of research in this area. Together, this information allowed the researcher to understand the composition of the sample and establish a framework that will the investigator in comprehending the possible dynamics at play with the sample. Further, at the end of this section, the researcher described limitations and made suggestions to ensure a higher probability of study recruitment success.

Bronfenbrenner's Ecological systems theory characterizes five environmental systems in which an individual interacts and aids in examining individual's relationships within extended communities and wider society (Bronfenbrenner, 1977, 1979). This model frameworks five systems, as seen on *Figure 4*. The investigator took an analytical approach to the data to answer questions within the framework of the microsystem, mesosystem, exosystem, and the macrosystem.

Chapter 3 - Findings

Descriptive Summaries

In the following paragraphs, the researcher will first discuss descriptive findings of demographic and neuropsychological data from the sample that participated in the study. However, given that the purpose of the current project is to examine the limitations of the study from an ecological perspective, the remainder of this section will discuss the findings with respect to that objective.

Participants were 17 patients (women = 8) from the HIV clinic at SSC who had an average age of 43 years ($M = 43$; $SD = 5.4$; range 29-49 years) and all reported having undetectable viral loads. From the screening interview, the investigator found that ten identified as Mexican and seven reported being Puerto Rican. The average level of education was a 7th grade ($M = 7.1$; $SD = 8.5$) level with a range from 3-15 years. On average, participants had been diagnosed about 10 years ($M = 9.88$; $SD = 7.3$) before the testing date and had been taking medications for just as long ($M = 9.5$; $SD = 7.1$). The average monthly income of the group was about three hundred and fifty dollars ($M = 341.1$; $SD = 278$) with a small range (Range 0 – 800 dollars). Wilcoxon-Mann Whitney Tests were conducted for demographic variables between participants with and without complete data. As seen in *Table 2*, the results revealed there were no significant differences in demographics between groups ($p > .05$).

Participants completed the Antiretroviral Medication Adherence Survey that enumerated missing doses of HIV medication (Mathews et al., 2008). Specifically, items in this measure ask patients to list the medications they are currently taking and indicate the number of doses missed for each medication. All participants reported having missed 0 doses in the last several months. All participants also reported having undetectable viral loads.

A close analysis of the neuropsychological assessments revealed several findings. The Hopkins Verbal Learning-Test Revised, which examines memory of verbal unstructured material, was the only test that all participants with useable data completed without any apparent difficulties. For the general age bracket for our participants, all scores fell within the low average normatively, which indicates that performance was as expected for their level of education, as detailed in norms of Spanish-speaking individuals (Cherner et al., 2008). Specifically, and as shown in *Table 3*, participants remembered a range of 17-29 (out of 36) words during the three immediate recall trials. These scores suggest that participants were generally remembering the items on the word list. After a 20-minute delay, participants remembered a range of 5-11 of the 12 words on the list, suggesting some difficulties in recalling words. However, recognition memory scores were between 9-12 words, which suggests that generally, participants recognized most words which suggests the presence of preserved verbal memory functioning. In contrast, performance on the BVMT, a memory test of unstructured visuospatial material, fluctuated more with scores ranging from 0-30 points (out of possible 36). As shown in *Table 4*, Delayed recall scores also had higher variability and ranged from 1-12 points (out of 12 possible). Relatedly, recognition memory ranged from 2-6 points out of 6, suggesting that participants had difficulties encoding visual information. This analysis of the data revealed that some participants missed only minor points but captured the general designs, whereas the remainder had scores that were lower than 4, which also supports the suggestion of poor encoding and retrieval of visual information. Those who provided valid data demonstrated adequate performance (Cherner and colleagues, 2008).

A qualitative exploration of the computerized tasks revealed significant challenges in completion. As shown in *Table 6*, the reversal task was discontinued for 83 percent of the participants who attempted it as they never developed a mental set of the discriminations and met the 500-trial limit imposed on the task. Similarly, the transverse patterning test was only successfully completed by one participant and the remainder of the participants also reached the 500-trial asymptote or testing was discontinued due to possible random answering. These were two tests that the researcher did not have difficulties administering and completing with healthy younger and older adults in a previous study (Gracian et al., 2016). Of course, determining the etiology of the deficits on this task is complicated, as I do not have enough information to determine if poor completion rates were due to a general cognitive deficit or their level of technological/computerized experiences. Notably, the neuropsychological data the researcher did obtain shows that the participants were able to successfully process and encode verbal information, whereas they had more difficulties with visual material. Thus, it is also possible that the visual memory inefficiencies observed on testing are due to challenges in visuospatial reasoning that could be related to participant developmental or medical history. A 2014 article by Ravindran and colleagues revealed that children with HIV who were being treated with ART had visuospatial difficulties compared to seronegative counterparts, suggesting that the visuospatial deficits in the sample could be related to their existing HIV diagnosis. However, recent neurocognitive articles did not mention nor examine visuospatial abilities in relation to neurocognition, either among children or adults, suggesting a point of expansion in the literature (Andrade et al., 2012; Marquine et al., 2018).

Berg's card-sorting test was the most difficult to successfully complete for most participants. On this test, and as shown in *Table 7*, participants were evaluated on how many categories were completed (out of 6) and how many errors are committed. Heaton and colleagues published norms in 1996 that provided estimate conversions of the card sorting test in Spanish-speaking adults (Artiola et al., 1996). Although imperfect because norms are based on paper-and-pencil version of the card sort, and I administered a computerized form, it is the best estimate that I can provide in terms of a normative context. After reviewing general performance and norms, the group performed within what is also expected given the culturally corrected, Spanish-speaking, Heaton norms (Artiola et al., 1996). In detail, from the participants who attempted this test, only two individuals completed six categories, and eight individuals only completed 1-3 categories. Similarly, this group completed one to four failures to maintain set errors which indicated that the participants committed an error due to a lapse in attention and forgot the category they were completing. Also, in general, all participants were perseverative in their responses, indicating that they were making the same mistake regardless of the negative feedback and that they were not attempting new strategies when they were told their current strategy was incorrect. Further, most participants also had more total incorrect responses than correct responses, which also provides evidence of lack of test and instruction understanding. Together, these patterns could be related to difficulties in comprehending test instructions or executive functioning problems. Although these patterns are normative to this population, as patients with HIV have impairments in completing card-sorting, mental flexibility tests, especially if they are not adherent to medications (Huerta et al., 2016).

In conclusion, descriptive findings indicated that participants were mostly middle-aged, from a low- income household, were immigrants, and had never participated in previous neuropsychological studies. The investigator also found that the HVLT-R was the single test in which participants did not have difficulties understanding test instructions. In contrast, the computerized tasks, and the card sorting test were difficult. Next, he will review Bronfenbrenner's Ecological theory and discuss recruitment and participation challenges presented through the lens of this theory.

Study Framework viewed through the Lens of Bronfenbrenner's Ecological System's Model

Bronfenbrenner's Ecological systems theory characterizes five environmental systems in which an individual interacts and aids in examining individual's relationships within extended communities and wider society (Bronfenbrenner, 1977, 1979). The investigator took an analytical approach to the data to explore the reasons behind the difficulties with recruitment and collecting complete and valid data within the framework of the microsystem, mesosystem, and the macrosystem.

Microsystem

In the following paragraphs, the investigator examined the components at play during the testing session which comprised the microsystem representing the research participant as one actor and the researcher as the other actor with whom the former interacts. The aim was to examine the details that could have affected testing performance in the study session. For instance, which tests did participants have difficulties with and what were these difficulties?

What intrapersonal factors, such as the use of mood-altering substances or mood disorders, affect participant performance during the study session? How did individual variability in participant health and access to resources affect performance? Providing answers to these questions will help disentangle elements that affected performance in the study session that led to incomplete data.

The Environment

The testing sessions occurred at the SSC, an environment that was presumably familiar and comfortable for the participants. The SSC is a low-cost clinic that offers high quality care, health education, and social services to residents of the multicultural neighborhoods on Milwaukee's south side. Comprehensive services include adult and pediatric medicine, behavioral health services, social services, women's health, and HIV prevent and treatment. Participants can pay out of pocket or use Badger Care state insurance to cover the costs. All prospective participants were given the option to meet either at SSC, the public library, or at UW-Milwaukee. All participants opted to meet at the SSC because it serves as a safe space for patients and it is a place that is comfortable for them. However, a few participants indicated that a concern about the study was that they preferred to be discreet about their HIV diagnosis and were hoping we met somewhere that would not unveil their diagnosis, such as SSC, as their attendance could be for any general medical reason, not circumscribed to HIV. Participants reported that only their case workers and doctors knew of their diagnosis and stressed the negative impact on their social life that revealing their diagnosis would do. All participants were referred to the study by a case worker whom the researcher had worked with before at the Medical College of Wisconsin when he was conducting a neuropsychological assessment

in Spanish for a participant who was undergoing moderate brain dysfunction. She indicated that participants were wary of participating in HIV studies, but that they were more willing and comfortable to participate when she reported to them that she knew who the investigator was. Patients were reportedly more interested in participating when participants were told that the researcher was of Mexican descent, and Spanish-speaking since most of the students who attempt to collect data from clinic populations are either non-Latino, do not speak Spanish, and require an interpreter. The researcher had limited time to conduct the interview and testing session, so he tried to work quickly and efficiently while maintaining a general interest of the participant. All participants were interested in chatting and learning about the investigator's life story and academic trajectory. Several indicated their pride in learning that he was Mexican, first-generation student who remained connected with his cultural and religious roots and is interested in working with Spanish-speaking participants. The consent process went relatively quickly because the researcher had explained all risk, testing procedures, and payment on the phone. Participants generally did not have any questions prior to beginning.

How did participants perform on the neuropsychological testing?

All participants reported they had never had any neuropsychological testing done before, so all were naïve to the tests that were being administered. However, the investigator has administered the same tests to healthy and patient populations in research settings. Notably, participants in this study had difficulties completing the complex Medication Management Ability Assessment that has successfully been used in other Spanish-speaking individuals (Thames et al., 2010). The patient population the

investigator recruited was demographically different, especially in ethnic composition, level of education, and English language speaking abilities, compared to populations he had evaluated and the sample from Thames et al., 2010. Additionally, the patient population from SSC offered feedback that he never received from the other sample. For example, some participants indicated that the instructions were very detailed and long. The MMAA is a difficult laboratory test of an instrumental activity of daily living, and some participants were visibly overwhelmed with the instructions. As shown in *Table 5*, the MMAA total score and pill scores had a higher standard deviation and suggestive that the participants committed errors. If interpreted as a reflection of true adherence, it could be predicted that true adherence is impaired. However, participants reported having perfect adherence, and so this finding is discordant with self-report measures, which is probably related to the difficulty of the MMAA task. Some indicated that the medication regimen on the test was more difficult than their own medication regimen. For instance, the most difficult regimen someone reported consisted of taking three pills in the morning and one in the evening. The remainder of the participants indicated that they took all their medications at one time at any given time of the day. All were taking one antiretroviral combination medications, and participants who were taking other medications were either psychotropic medications or blood pressure medications. According to CDC information, initial combination regimens for antiretroviral-naïve participants with HIV infection consist of a cocktail of 3 ART medications in the form of a single pill (Kemnic and Gulick, 2018). Most participants who participated in the study had been taking medications for several years and were already had simple prescription instructions. The researcher had used the MMAA in a research setting in both San Diego, CA and

Milwaukee, WI previously with healthy young adults, healthy older adults, participants with Parkinson's disease (PD), and participants with Huntington's disease (HD). Those participants were all English speaking and most had at least a few years of college education or more. Participants in these studies also appeared to have a higher level of literacy in general and did not have difficulties understanding the instructions or completing the task. Aside from participant populations with PD and HD, healthy younger and older adults reported being generally healthy and served as controls for PD and HD participants.

The verbal learning test appeared to be the least difficult test for participants to complete. Participants did not have difficulties understanding the instructions, they reportedly knew and understood all the words used, and some indicated that it was the most straightforward. The investigator used version two that included words that are frequently used in the media and that have the same meaning across Spanish dialects. This version includes spirits (alcohol), kitchen items, and weapons. The visual learning test was also difficult for participants. In the instructions, participants were told to study the images for 10 seconds, and only after the 10 second period and the display was removed, were the participants allowed to draw the figures. When participants were asked to provide drawings, many left the pages blank indicating they could not visualize and reproduce the images. It is possible that this might be due to a general cognitive issue, in which the participants are not able to reproduce figures as is often seen in people with memory retrieval problems. Nonetheless, a recent study with an HIV patient population from Colombia who was also Spanish speaking did not reveal significant differences in visual memory between seronegative and seropositive participants with

undetectable viral loads (Martinez-Banfi, et al., 2018). Further, one participant indicated that she did not see the point in studying figures and then drawing them. The investigator tried to explain to him that drawing figures is something that he can use to objectively examine his visual memory. He said that in school he had not copied figures since grade school, and that tracing was associated with simple tasks for slower people. The researcher assured him that these are the kinds of tests we administer to people of in the United States. This situation probably has a cultural explanation, as this participant is Mexican and went to school outside of the United States. The participant was speaking practically and did not appear offended or disturbed. Rather, he was inquisitive about the process. However, it is a possibility that if somehow this experience was odd or unpleasant some participants might have shared this information with their case workers or other participants. Further, if the larger context is considered, this experience could affect the participant's perception about research and impede their participation in other projects. Then, through "word-of-mouth" this reinforces negative thoughts about research participation.

Participants demonstrated difficulties completing computerized tasks. Some participants were able to complete the reversal task and/or the transverse patterning tests with little difficulty. Most, however, could not complete either the reversal or transverse patterning tests. This could be due to general cognitive impairment, but the researcher suspected that it could also be due to educational level. In the pilot study, scores on RT and TPT were significantly related to level of education, as participants with higher levels of education had better scores. Most participants in this study had an elementary school level of education, and all participants in the pilot study were college-educated or higher.

Perhaps the investigator chose inappropriate computerized tests to do with a population that has lower education, and ways to make these tasks simpler and more accessible need to be found. Another task that was difficult for participants was the BCST. In the BCST, participants are given two stacks of 64-cards each, and they match those cards to one of the four key cards that are selected by the administrator. The participants are given few directions, but the overall aim of the test is for individuals to figure out that the cards must be sorted by color, shape, and form, in consecutive order. In general, this test is difficult for Spanish-speaking patients in clinical settings, when patients have difficulty following the instructions and following-through with the demands. Specifically, the participants had difficulty understanding the concept of sorting or categorizing cards, and in the clinical setting this is typically attributed to lower literacy and level of education. However, there have been times in the clinical settings when participants with lower education complete the task seamlessly, but this was not the case for our study. In general, the task requires that the administrator provide very little instruction, and I am unable to direct or provide scaffolding for the participant. For this study, the score profiles suggested that participants were randomly placing cards in a trial and error fashion to seek ways to categorize the cards. Additionally, once a category was obtained, participants tended to persevere to that category, and not switch when necessary. For example, once participants were matching to color, they failed to find a new category or way in which they matched because some cards match for both the previous category (color) and a new category (form) at the same time. It is possible that some participants were unable to make sense of this information due to challenges in mental flexibility that could be due to HIV, age, or other factors. However, some participants can do this test

and were hindered by the lack of instructions. At the time of the interview, most participants reported that they had impaired vision or that they required corrective lenses. All participants were asked to bring their glasses when they come to testing, but it is important to understand that many low-income individuals are unable to afford corrective lenses. When this became an obvious issue, the researcher bought three drugstore “cheater” glasses at various prescriptions that participants could borrow to better see. A total of five participants used the glasses that were provided. This ensured that participants were performing at their abilities and were not hindered by their visual challenges.

The questionnaires were challenging for some participants to complete, especially regarding current drug use. At the study session, some participants appeared to be under the influence of a substance and were either evasive about their drug use when asked about it, or indicated they were uncomfortable answering those questions. When the investigator suspected that a participant had ingested a substance that impaired their learning and thinking for the study session, he moved the substance use questionnaire to the beginning to get a sense of their use. If the participant appeared to be under the influence of a substance, or the participant reported using a substance that day, the study session was terminated, and no further testing was conducted. This happened on four occasions and these participants were invited to return at another time when they were not impaired. None of these four participants returned later. No difficulties understanding the questions were reported by the participants when completing the anxiety and depression questionnaires. However, some participants did become teary-eyed when reporting some of the symptoms they were experiencing.

How did the SSC case manager influence patient participation?

In the following paragraphs, the researcher will examine another component of the microsystem: the relationship between the participants or potential participants and the case manager who played a primary role in referring patients to this study. The aim was to examine how participant and case worker interactions could have influenced recruitment for the study. For instance, what was the quality of the relationship between participants and case managers? How is their rapport and participant-practitioner alliance? What factors influenced participants to participate in the study? What extant barriers might have been impeded potential participants from contacting me to either learn more about the study or enroll into it? Exploring these questions will help disentangle elements that might have affected participant recruitment.

At SSC, case workers assist participants in their medical and medication management in the context of their HIV treatment. When cases are more complicated, they also assist participants with other ailments or medical concerns they may have. The case manager who referred participants to the study reported having good relationships with the participants they referred, and the participants asserted that the case workers were instrumental in their treatment. Other case workers were not successful in recruiting participants for our study. The researcher had limited information regarding the reasons why participants decided to not call and undergo the screening procedure to participate in the study. The case manager indicated that some participants are generally not interested in participating in any research, even including internal SSC studies. However, since the participants for this study were referred to the investigator by a trusted case worker with whom he had worked closely, he presumed that they entered the screening procedure with a level of familiarity and trust. That

is, the case worker informed them of the researcher's role in the study, the aims of the study, and assured them that confidentiality and respect would be practiced with their identity, medical records, and participation. From even before the participants agreed to be screened, they were aware that they would be releasing private and personal information to the researcher, and the researcher was a trusted individual by the SSC and the case workers. Patients were also given a description of the investigator's role in this study (Mexican graduate student in psychology from UWM) and his career goal of becoming a neuropsychologist. It could be possible that the researcher's level of education and role intimidated other Latinos. Culturally, often times individuals who feel they have less education than others have difficulties communicating and interacting with people who they feel have a higher education. Alternatively, they could also act with high respect, but nonetheless, it could be likely that his status as a doctoral student (rather than as a professor, for instance) and/or the researchers' relationship to UWM could have deterred potential participants from calling. It is difficult to know specifics of their lack of interest because they were not asked but based on the literature on Latinos and research participation, it can be inferred that it could be due to several factors. For instance, Latinos experience stigma related to research, especially in the context of medical conditions and infectious diseases HIV. Additionally, there is a general distrust of researchers and practitioners, especially if they are white or they do not speak the language they speak (George et al., 2014; Waheed et al., 2015).

Success in recruitment was largely contingent on the case worker assigned to collaborate with me. She was an early career master's level social worker who was eager and passionate about helping disadvantaged participants who are HIV-positive. She reported that she was

excited about the study because she felt it was contributing to advancing treatment outcomes for Latinos with HIV. She thought recruitment would be simple especially because of the cash incentive. She was incredibly supportive of the researcher's endeavor to obtain a PhD and told all her recruits that a young Mexican PhD student was conducting this work. Every single participant that was screened for the study was referred by her. She also facilitated participant interactions and completion of paperwork. The tone and disposition with which the case manager presented study information influenced participant participation. There were data available to support that the case workers attitude and disposition about the study had a negative effect on recruitment. Nonetheless, as far as the researcher saw, she was committed and excited to assist and reported that she was excited about the results. Professionally, she was also excited about his position as a graduate student and respected his journey to obtain a PhD.

These findings provide evidence of the importance of the case manager and participant relationship in recruiting participants for these types of studies. Rapport in the practitioner-patient relationship, cultural factors, and method of presentation were some of the points that were discussed as possible elements affecting recruitment and retention. This information will be especially important for researchers who are using third parties to recruit.

How did the researcher influence data acquisition from the participant?

In the following paragraphs, the researcher examined another component of the microsystem: the relationship between the participant and the researcher. The aim was to examine which aspects of his interactions with participants during the screening and testing sessions could have contributed to their challenges in completing the study tasks. For instance, often new medical symptoms that would disqualify participation in the study were

reported at the study session and had not been previously discussed during the screening procedure. Did patients underreport symptoms during the screening procedure? If patients did underreport, then why? Did participants exhibit any hesitation or discomfort when they were asked personal questions about psychological and psychiatric information? Could research demand characteristics (e.g., patients think they gain a sense of the study and start acting in ways that they think will influence the results, patients act in ways they think researchers want them to act.) and anxiety affect participant performance? Exploring these questions will help disentangle elements that affected participant performance and study completions.

The screening phone call was the first interaction the researcher had with participants who were interested in participating. This was the first opportunity to develop rapport with the prospective participant because the researcher was asking invasive and sensitive questions from the beginning. After introducing himself and indicating that he knew their SSC case worker well, the researcher told participants that he was born in Mexico and migrated to the United States when he was very young. Additionally, he shared that he was Spanish speaking, and that an aim of his career goals was to become a Spanish-speaking practitioner for our community. The researcher shared this information in hopes that the participants would feel more comfortable and related to their experiences as immigrants and Spanish-speakers. The screening procedure took a little longer than typical because it was structured as a mini-clinical interview in which I asked detailed questions and listened to their stories. Prospective participants were willing to answer most of his questions, but they were also interested in sharing their stories, including their challenges with HIV and their experiences in the community in Milwaukee. Some participants shared that their HIV

diagnosis came as a surprise, because they did not engage in any perceived risky behaviors, such as drug-use or unprotected sexual activities. In fact, some were infected by their long-term partners with whom they are still in relationships. Others were straight-forward about their engagement in risky behaviors that placed them at risk. The most difficult questions to answer for most participants were regarding current and existing drug use. Although most participants seemed accustomed to being asked questions about substance use, it must be difficult to answer such questions for someone who they had never met in person (as these conversations happened over the phone) and someone who is part of their ethnic group, as substance use is strongly prohibited and discouraged in Latino culture. The researcher asked substance use questions in a clinically sensitive way to remove the charge of the action, but on occasion the participants hesitated to be fully honest about their current and existing experiences with drugs. Although the stipend for the study was not at an amount that would be considered coercive, participants appeared to be concerned that a substance use history would disqualify them from participating in the study, so the researcher ensured that he told them before the screening process that drug history does not disqualify them from participation. However, he did indicate that participants had to be sober when they partook in the testing session, and he implored that they be fully honest about their drug history. Three participants reported that they would be unable to come to a testing session sober because their use of medicinal marijuana was due to pain and anxiety. The researcher acknowledged their time and effort and told them they would not be able to participate. Participants who did not qualify for these reasons were typically not upset and one even acknowledged that he would have used the \$30 payment to buy more drugs. There were other reasons, such as learning disabilities or severe psychiatric conditions that often-disqualified patients from

participating. The researcher was honest with every participant about why they did not quality and answered their follow-up questions if they had any.

The researcher attempted to be straight-forward and non-judgmental in his approach, but even then, some questions are very charged regardless of how they are asked. For instance, the topic of substance use is difficult to discuss, especially when participants had to report their current use and when culturally, substance use is stigmatized and rendered unacceptable. During the screening process, participants were asked to answer yes or no to using any drugs currently without going into detail. If they said yes, they were asked to abstain from using any substance that would impair their performance throughout the study session. However, other details were not asked until the interview portion of the study session. At this interview portion some participants did not elaborate about their substance use and thus important information that would disqualify a patient from participating was learned after enrollments had occurred. Others were clearly experiencing an effect of a mood-altering drug during the testing session, as evidenced by disorientation, sleepiness, and difficulties attending to the tasks, and did not admit to using. In these situations, the study session was discontinued, and the participants were asked to reschedule to a later time. Specifically, the researcher said that they looked tired and that these tests are affected by sleepiness. Then he indicated that it would be better if they were not sleepy to retain the integrity of their performance, and that we should reschedule to a later time. In all of these cases, the individuals rescheduled but did not return to complete testing. This failure to reengage suggests that the participants may have been uncomfortable with sharing this information or they were not willing to abstain from using any substances that were affect their performance the day of testing. Alternatively, they could have been annoyed that the

researcher stopped the first study session and decided to not reengage. In general, participants varied in their willingness to share their substance use information and it has shown to be a central element that influenced participation and retention in the study.

At the end of the testing session, the researcher always asked participants for feedback about the experience. In general, the participants reported they enjoyed the experience and found the tests interesting. Others commented on the difficulty of the test, and a select few wanted to know what specific tests measure. The researcher made every effort to engage the participants and read their social cues in ways that make the participant feel the most comfortable. With some, it meant the administrator needed to briefly speak about their day or their family. With respect to others, it meant the researcher was quieter and got through the testing with less chatter. Nonetheless, the researcher placed his best effort in making the environment comforting and welcoming for the participant to complete the study session. Interestingly, no one asked about what the researcher had already learned about the study, or what the forthcoming steps would be. Some participants took this session as a forum to voice concerns about the clinic (wait time, cost, participant care, etc.), or make suggestions on how to improve their care (depression groups, substance use therapy, etc.). The researcher forwarded all of those suggestions to the director. This does not mean that participants were not uncomfortable. It could be likely that participants felt some discomfort and did not vocalize it. Nonetheless, the investigator is confident he did his best to act in clinically competent ways to ensure their comfort and respect.

In the previous paragraphs, the investigator discussed how relationships among actors in patients and participants' microsystems affected recruitment and collection of usable data. Specifically, he described the relationships among participant and the case manager,

participant and researcher, participant and neuropsychological tests, while also describing the environments in which these interactions took place. In general, the findings suggest that participants could have experienced discomfort that affected their enrollment and data completion. Similarly, despite the researcher's efforts to establish a respectful, kind working relationship and respecting participant boundaries difficulties existed that were monitored to the best of his ability. These descriptions consisted of elements that directly impacted the participant because they were involved. Next, the researcher will discuss additional levels that account for actors that might not interact with the participant directly, but that nonetheless influences them.

Mesosystem

The mesosystem is composed of the interactions between the different microsystems in which an individual interacts. In this case, the microsystems in which the participant is involved that also affected recruitment and retention for the dissertation are the SSC and UWM, and thus the relationship between the researcher, case manager, and clinic director. Both establishments attempted to establish a professional relationship to recruit participants to complete a research study to advance the neuroscientific literature. The SSC HIV clinic determined that they could grant the investigator access to their patient pool and related records to complete the study as it would be advancing the literature about a minority population whose findings often go unpublished. UWM granted the researcher access and resources to carry out this investigation of the SSC HIV patient population. Thus, in the following paragraphs, the investigator examined the professional relationship between the case worker and HIV clinic director from SSC with the researcher from UWM. For example, what is the professional relationship history between

colleagues from UWM and the SSC, with Latinos, participants with HIV, or other related diseases? Do colleagues from UWM and SSC have good working professional relationships? Providing answers to these questions will help disentangle elements about the relationship between UWM and SSC that affected recruitment and participant performance.

How did the UWM researchers and SSC colleagues influence recruitment?

The relationship between the researcher and SSC colleagues facilitated the development and recruitment for the dissertation. Since the initial interactions everyone was collaborative, friendly, and committed to ensuring that the dissertation succeed. This application falls under the mesosystem because the relationship between a UWM researcher and HIV clinicians at SSC is only remarkable for participants because they resulted from a research collaboration that indirectly influenced them. First, the researcher met with the directors to determine if the study was a possibility. Once they established feasibility, the investigator wrote a proposal, defended that proposal, and obtained IRB approval. At this time, the researcher had another meeting to commence recruitment and was assigned to work with a case manager. He communicated to the case manager information about the study, the qualifications, rewards, and expected experience. All interactions were always positive, friendly, and collaborative. All case managers in the HIV clinic were excited that their patient population was being examined and they were looking forward to the results. Both researcher and case workers were excited to begin recruitment, and we worked collaboratively to communicate with patients and schedule sessions. Participants noted a few concerns about practitioners or suggestions about social programs that they asked the researcher to forward to the HIV clinic directors.

Recruiting minority participants, including Latinos, is a consistent challenge reported in the literature and now several researchers have developed interventions designed to improve

recruitment (Brown et al., 2018; Garza et al., 2017; Lopez-Owens et al., 2018). Traditionally, increasing the participation stipend is one of the first steps to improve recruitment. As this was not an alternative for the current researcher, he advertised and recruited from SSC. As previously discussed, there is no evidence that any interaction the case worker affected recruitment negatively, and the same stands for the rest of the staff and interactions. Similarly, the study was as advertised as it could have been to all HIV-positive patients. However, the study sample behaved as expected and similarly to what is encountered at a Spanish neuropsychology clinic.

This section described the professional relationship between SSC and UWM that indirectly influenced the participants as they are part of a convenient sample recruited from SSC because patients thought they would be interested in participating. This indirect influence described the mesosystem, as it characterized the relationships between two microsystems that individuals are part of, directly or indirectly. Here, the researcher discussed the collegial relationships between UWM and SSC. Next, he will discuss how the Exosystem, the next level of Bronfenbrenner's ecological systems model, can be used to explain the difficulties with recruitment and data collection.

Exosystem

The Exosystem represents elements that can influence an individual indirectly as a direct relationship is not required. In other words, the elements might appear unrelated to the individual, they can indirectly serve as an actor that influences his or her actions and behavior. For example, an individuals' life could be indirectly affected by the difficulties that his or her spouse, or partner, or family member is experiencing at work, with the law, or even another major institution. For this part of the exploration, the

researcher will be discussing aspects that could have affected the participant unbeknownst to them. he will be discussing the professional relationship between the SSC and UWM. In the context of this interpretation, the researcher wants to highlight that the elements he will discuss might not necessarily be active compounds but could also be a product of simply human existing.

The bigger picture: medical and academic institutions

The professional relationship between the department of Psychology at UWM and the SSC remains in the nascent stages because of the absence of collaboration in the past years, particularly among Latinos and Latinas. UWM Psychology has had few faculty members who are Spanish-speaking and none who identify as Latino/a/x. In fact, since 2010, there have been just one other clinical psychology graduate student who has either conducted research studies at SSC or clinical work. As such, the community (and the clinic) are largely unaware of the type of work that is conducted at UWM. Thus, there is less knowledge and trust between both institutions. There is a large literature that suggests that, in general, Latinos tend to mistrust research and medical institutions, especially when they do not have any faculty, providers, or students who speak their native Language and understand their culture (Levkoff and Sanchez, 2003). Thus, collaborative relationships between the two institutions are underdeveloped; there is much room for expansion. However, developing trust between Latino participants and research institutions is not possible without the integration of a language that participants use to communicate and a delivery that is presented in a culturally sensitive way (Garza et al., 2017). This becomes further complicated due to the lack of continuity of professional relationships between both institutions. For example, this project allowed

our laboratory to establish a good relationship with the HIV clinic at SSC. Previously, another student from UWM completed a clinical practicum at SSC with Spanish-speaking participants. She performed brief interventions with underserved, underrepresented, and lower income individuals with significant psychopathology. Other than these two experiences that served to strengthen a professional relationship between UWM and SSC and some exposure of UWM to Latino participants in the Milwaukee community, there have been no other efforts in recent years.

Once recruitment stalled with the present project and the researcher struggled to enroll enough participants, he scheduled several meetings to attempt to resolve the difficulties with recruitment. Recruitment commenced on October 2016, and follow-up meetings took place on 2/23/17, 4/6/2017, 6/7/2017, 9/7/2017. The first meeting effectively took place 4 months after the study began recruiting. As participants began reporting positive experiences with the research study, the SSC HIV clinic staff began to suggest that the researcher attend other meetings or events where participants would be present and offer an opportunity to recruit. The first event was an LGBTQ picnic event that was hosted by SSC. At this event, participants from the HIV clinic gathered to get to know each other, and to meet the providers. This event was planned because several participants had indicated that they would like to meet other people who are undergoing treatment for social support purposes. This event served as an opportunity to showcase UWM Psychology and demonstrate to the community that the researcher is interested in effecting change in the mental health outcomes within the Latinx community. Similarly, this was an opportunity to demonstrate how our research studies could be used to advance the behavioral sciences with Spanish-speaking participants. A conversation

occurred in which participants reported feeling more comfortable around Spanish-speaking individuals, as most of their medical providers in Milwaukee, Wisconsin have been English-speaking only. The HIV clinic director indicated that this would be an excellent way to recruit multiple people. It is important to note, however, that attendance was low (n=13) and much of the interaction occurred between case workers and providers.

The current project was set within the SSC because all relevant HIV biometric and medical participant information was already readily available for use. Additionally, SSC partners with a specific pharmacy that would allow us to access prescription information. During the initial discussions with SSC regarding the feasibility of this project, the director indicated that there was a pool of approximately 150 participants available for recruitment. Advertisements for the study were present in the participant waiting area and in the office spaces. Additionally, the advertisement for the study were printed in quarterly bulletins and gift bags that were given to participants at different events. In hindsight, the researcher should have sought to advertise via other avenues. For example, a posting on craigslist that was renewed intermittently to recruit SSC HIV participants who are craigslist users. Fliers could have also been posted in public areas with large circulation of Latinos in Milwaukee. Lastly, Facebook and Instagram postings could have also increased the visibility of the postings on social media (Adrian et al., 2019; Gaupp-Berghausen, et al., 2019).

Macrosystem

The macrosystem is a framework that describes the culture in which individuals operate and the social factors that influence their daily activities and development (Bronfenbrenner, 1977, 1979). Cultural contexts that are applied in the macrosystem include industrialization, socioeconomic status, poverty, politics, and ethnicity. By nature, the macrosystem evolves over time, because each successive generation may change the macrosystem with a variety of social, cultural, political, or economic factors. In the following paragraphs, the researcher examined how societal, cultural, and political factors that affected the individual at the different levels. In the context of the study, the researcher analyzed the components of the macrosystem that affected recruitment and participation in the study. For example, how do Latino Spanish-speaking participants with HIV feel about academic research? Might fear of deportation have affected recruitment? What are the competing demands that could have affected recruitment and participation? Was the compensation for participation sufficient to offset the participation burden and competing demands? Providing answers to these questions will help us to understand the indirect influence of the macrosystem on recruitment and participant performance.

Stigma Associated with HIV

HIV infection is associated with several levels of stigma that can be specific to certain cultural populations. In Latinos, an HIV diagnosis has a negative connotation as it is related to an infectious disease that is transmitted through sexual relations, historically in gay men. Misunderstandings and prejudices about HIV still exist, especially about its transmission, and it is not uncommon for patients with HIV to experience guilty, embarrassment, and even worry about peer reactions to their diagnosis. Since the

researcher is a seronegative Latino gay man, his presence could have placed participants in an uncomfortable circumstance. Given that the aim of the study was to characterize neuropsychological findings in HIV infection and their relation to medication adherence, participants understood that the knowledge gained from the study's findings should benefit people like themselves. However, participants may have found it troubling and embarrassing to sign up for an HIV study because of the cultural context it was placed in. Latino patients might be prone to live with guilt and shame because of their diagnosis and there was an unspoken understanding of the difficult implications if this diagnosis were to be unveiled to family and friends (Williams et al., 2004). Some participants talked about HIV stigma in general, and it could be possible that this stigma produced anxiety or other symptoms that affected their ability to concentrate and complete the tests. In contrast, participants could have been comforted by our overlapping cultural identities, since all participants were Latino, and most were Mexican. Especially in Milwaukee where the Latino population is smaller, it is always a pleasure to run into a fellow *paisano*. Often, interactions between Latino strangers in a less diverse environment are relieving, as it becomes easier to reflect and communicate. The researcher felt that connection with the participants in the study, and he acted in accordance with cultural values (using formal pronouns, being a good host), and participants seemed comforted by this.

LGBTQ Influences

Since the past and current directors of the HIV clinic identify as LGBTQ, it is also likely that participants perceived the researcher's gay identity favorably (although he did

not directly discuss it) and perceived him an ally. There is no reason to believe that the researcher's sexual identity deterred participation or affected data collection, but it certainly is a possibility given that homophobia still exists. There exists a complicated history of homophobia related to HIV infection that often leads to strong opinions and emotions. Participants did not know the researcher was gay before meeting him, and he did not receive any cancellations, but it could be possible that participants who did not return to complete testing did so because they were uncomfortable with what they perceived the researcher's sexual identity to be. Relatedly, only some participants asked the researcher to disclose his HIV status at the study session, as they wondered if that was his inspiration for the project. The researcher did not receive any questions, nor did he disclose his HIV status during any other interactions.

The role of education in Latino Culture

Education is a complex construct that is affected by several sociocultural variables, especially in Latinos. There exists a complex relationship between Latino traits and attitudes about academia. For example, machismo is associated with less positive attitudes about education and poorer academic outcomes (Ojeda et al., 2011; Piña-Watson et al., 2016). The status of an educated person in Latino culture is thus, complicated, and there is a potential for a special type of respect that is awarded to individuals with higher levels of education. In the same vein, some individuals might resent highly educated people because perhaps they did not have the same resources and access to an education. Individuals might also feel as if people with higher levels of education cannot relate to them, as education is associated positively with income.

Although participants did not have any detailed personal information about me, they knew that the researcher was a PhD student at UWM who was looking to complete a dissertation project. Additionally, they were privy to his collaboration with SSC, and it thus might have appeared that he had special access and professional relationships with important administrative individuals who grant him access to work in SSC. It is possible that the formality of research and health care, and the researcher's perceived status because of his educational experiences, dissuaded patients from calling to enroll or discomforted participants during the study session. Nonetheless, there exist no data to support these claims. It remains important to consider cultural factors, such as perception of education and researchers, for future research projects.

Immigration and Deportation

The fear of deportation is real to many participants from SSC, especially in this current climate. It is important to note that recruitment for this study commenced before the 2016 election in which Donald Trump was elected President; however, the anti-immigrant rhetoric was ubiquitous during the campaign. Although participants tended to have general worries about being in this country illegally, it did not seem like fear of deportation affected participation. This was the case for several reasons. First, participants were assured by the case workers that we were trusted individuals, our fliers indicated that legal status was not an issue, and all testing occurred at the SSC facilities. Universities in general are less associated with deportation incidents, thus there is less fear that they would be occurring at SSC or at UWM, especially compared to grocery stores, factories, restaurant examples that have been featured in the news. After the

election, however, there was more conversation in general that centered on politics and the future of Latinos in this country. Every single participant that participated after the 2016 election shared commentary about the new president, and in their opinion, the negative effects he would have on Latinos given the widespread disparaging narratives about Latinos in general and immigrants in particular.

Deportation and immigration status are important cultural elements that influence Latinos. In fact, members of the community will report through social media where and when ICE or other immigration officials are raiding for unauthorized residents. The current political climate has exacerbated fears of deportation with current events and anti-immigration rhetoric. Given its place in Latino culture, deportation and immigration status form a part of everyday life. This leads to a general desire to be invisible and act unnoticed to slip through the system. Thus, any invitation to make oneself visible is sufficient to deter participation in the study. Despite providing a comfortable, familiar, and safe environment, the general fear of revealing one's information when one's status in this country is precarious probably affects recruitment more than thought, and there is no cash reward that assuages this general angst.

In conclusion, deportation was a general fear of many of our participants (outside the scope of the study), as it was quite frequently discussed in casual conversation by participants during both the screening and participation phases of the study. It also forms part of Latino culture as individuals from this community are accustomed to having and protecting family members who are unauthorized residents. Thus, it is likely that it could have deterred patients from enrolling in the study.

Transportation

Transportation has been cited as a difficulty that Latinos experienced in research recruitment, and also appeared to be the primary barrier that most of participants confronted (Levison et al., 2017; Levkoff and Sanchez, 2003). Since access to personal transportation is a privilege, and structural, immigration, and economic inequalities prevent individuals from earning sufficient money to have transportation or prevents them from obtaining a driver license. In general, participants preferred to meet at the SSC to complete the testing session because it was a familiar place that was also located in their community. Although evening appointments were more convenient for testing because of work commitments, participants preferred to leave work early and meet at SSC to avoid transportation issues. UW-Milwaukee is only located 2 or 3 miles away from the SSC but participants reported that they would have to engage in a 1.5 hour journey to get to UWM via bus. Additionally, for those who drove their own vehicle, their primary worry was parking and parking tickets because they are aware of the hardships of parking on the east side of Milwaukee, especially by the university.

Child Care

Child care was another barrier that was difficult for participants to overcome. Some of the participants had younger children who were not in school, or they wanted to participate during times that school was not in session. Several participants asked about child care opportunities and indicated that this was a barrier for their participation in research studies and health care. This was especially difficult because children do not do well in these quiet, non-stimulating environments for very long. The study sessions lasted

reliably 2 hours and some participants reported that the inconvenience of traveling to the clinic, devoting two hours of their personal time to the study session, and finding child care was not worth the \$30 that were offered for participation. Thus, recruiting Latino participants for our study was difficult because our sessions interrupted participant's daily routines disproportionately and the costs of participating might not have been offset adequately by the \$30 research compensation that the researcher was able to offer. Also, recruiting from this populations is difficult if study sessions are scheduled only during normal business hours when people are generally at work, especially if \$30 does not cover the usual day's work earnings. For example, prior to the beginning of recruitment for the current study, I concluded recruitment for this study's pilot project. That sample consisted of healthy younger college students who participated for class extra credit or retired older adults who were invited to a research presentation of the study findings. That group completed similar tests and questionnaires but in English. However, that sample of participants consisted of mostly White and college educated individuals that presumably faced different challenges, experienced different needs, and confronted different barriers than our sample from SSC.

The SSC as a resource to the community

The SSC is a resource that is utilized by many Latinos in Milwaukee. Participants reported valuing SSC as it has been instrumental in their HIV treatment and even offers them access to other resources, such as food banks, housing, and transportation; this especially applies to participants who were both unauthorized residents and disabled by another medical condition who could not work or access social security benefits.

Therefore, they relied on food banks and shelters to live in Milwaukee. The SSC only operates during business hours (8am-4:30pm) and individuals probably ask for time off from work to attend appointments. Since the study only operated during those business hours, it is likely that the researcher recruited mostly individuals who worked the second shift and were usually available in the mornings. This also indicated that the pool of participants lacked access to those individuals who wanted to participate but that worked the first shift and had to take time off. It is also likely that the pool of participants the researcher was targeting did not have the type of job that offered flexibility to take time off as desired. This is a privilege that is not often experienced in lower-income families from Latino backgrounds. The investigator did offer evening appointments, but those meetings could not occur in the SSC because of the 4:30pm closure, and participants were skeptical about traveling in the evenings to the east side. Participant recruitment for this dissertation was probably affected by this phenomenon, and the findings are likely reflective of individuals who are unemployed or who work the second or third shifts.

Compensation for research participation

The modest level of compensation the researcher offered to participants may not have been sufficient to offset the competing demands of our participants. Some options were considered to attempt to balance some of these challenges. For example, the investigator offered to conduct home visits and complete the study sessions there. However, some participants did not have reliable housing, or they did not have an adequate space where the study session could be conducted. In other scenarios, participants had not revealed their HIV status to their housemates and/or families and

they were uncomfortable having the study session in there given the sensitive nature of the questions that were going to be asked. Another option that was discussed was offering participant transportation to the clinic to conduct the study session. However, this would require additional IRB review and after discussing this option with the HIV clinic director, she determined that this would not be a tenable option. Therefore, this strategy was abandoned. Child care options were also carefully reviewed, and we were unable to find a suitable sitter or alternative to aid with this difficulty.

In the previous paragraphs the researcher discussed elements of the macrosystem that influenced participant recruitment and data collection, Specifically, he examined participant experiences that were related to societal, political, and economic factors that indirectly affected them. Specifically, he discussed the general angst about immigration and legal status in Latino communities and its possible effect on recruitment and the researcher described general barriers to research participation that have been identified in the literature and that the researcher considered to be part of the barriers that affected recruitment for the study. The researcher also examined factors relevant to the business hours in which SSC operates, as this set of time limited access to participants with less flexible schedules. This concludes the findings section and next, the researcher will discuss the importance of the findings and offer recommendations to improve recruitment in this and other minority populations.

Chapter 4- Discussion

In this section, the researcher will discuss the implications of the findings after being conceptualized using Bronfenbrenner's Ecological Model. First, the trajectory of the research project and the implications associated with the design will be discussed. Next, the researcher will describe the quantitative analysis and their inferences from the ecological model. Then, he will focus on explaining the proximal processes within each ecological system and their relevance to the literature. Finally, the investigator will make research recommendations for best practices.

Bronfenbrenner's Model Applied

Bronfenbrenner's model was used to examine the influences that could indirectly and directly influence the likelihood of potential participants opting to enroll in the study as well as the likelihood of enrolled participants providing valid data for the study. During the data interpretation process, the researcher recognized similarities between the ecological theory and "Socially Responsible Neuropsychology (SRN)" framework he had used in the clinical context (Suarez et al., under review). Training under the SRN model focuses on providing equitable care to Spanish-speaking individuals and addressing the health disparities that exist due to structural, social inequalities. Under this framework, clinicians examine neuropsychological data in concert with psychological, psychiatric, cultural, linguistic, and social justice elements to capture patient experiences and described illustratively in assessment reports. In addition to utilizing tests and norms that have been validated with the population of interest, this model allows the user to capture important individual elements that explain neurocognitive performance, such as traumatic childhood experiences and exposure to toxins. The SRN model can be used in

conjunction with the ecological theory to determine the proximal processes (defined below) that contributed to the dissertation findings. For instance, the researcher examined the role that academic advisors, professional relationships, the university, and the researcher as an individual had on the findings. A notable element about Bronfenbrenner's model is that he initially incorporated the chronosystem to account for changes that individuals could experience across a broad stroke of time that includes historical events (Bronfenbrenner, 1986) though eventually this evolved into the process-person-context-time (PPCT) model. In this updated model that was used post-hoc to examine the findings, Bronfenbrenner suggested that (with respect to children, in particular) development is a process associated within the individual, the context in which they are situated, and any processes related to time, including landmark events, dates, and individual chronology. Next, the PPCT model will be discussed more in depth.

Process-Person-Context-Time (PPCT) Model Applied

The different elements of the PPCT framework cover a plethora of relationships across varying and overlapping systems in Bronfenbrenner's ecological model. Similar to the SRN model, PPCT model provides a framework to examine neuropsychological data in concert with psychological, psychiatric, cultural, linguistic, and social justice elements to capture the HIV-positive patient population that the researcher investigated. This framework enabled the researcher to address structural and social inequalities and other health disparities that contribute to the difficulties in recruitment and data collection. Next, the PPCT model will be described in the context of the present study.

The Process can be defined as any influence on the individual that is developmental. For instance, participants in in this study were all migrants who underwent the process of moving from countries in which the economic situation is generally bleaker in search of economic opportunities Furthermore, most are unauthorized individuals living in the anti-immigrant political climate with a stigmatizing medical condition, and thus the related stress occurs and varies across time. With respect to HIV, there are experiences unique to the disease process that occur across time (infection, learning about infection, treatment, etc.). These variables are likely to have an effect on cognition and are considered when making clinical conceptualizations under the SNR training model. The Person can be described by any intraindividual and interindividual influences that exists with any object, person, or symbol. For example, the researcher examined the meeting relationships that participants had, for instance with him or with a case worker, and found relevant details that were presented in the findings. He also examined the relationship between participants and neuropsychological tests, and he applied concepts from SNR to highlight important patterns and provide insight as to how they should be interpreted. The Context is any environment in which the individual exists, whether active or inactive, and in which they continue to have experiences with *proximal processes*. For instance, the institution of the SSC was a major element as the study was conducted there and the researcher was sponsored and supported by them. The study session itself was a context that was important, as behavioral observations that occurred during the study session are relevant even in the clinical context. A training philosophy of the SNR model is to educate others about it by exposure, such as talks and workshops. The professional relationship between SSC and UWM is a means to introduce the model to the Milwaukee medical and academic communities in hopes of extending access, equity, equality and social justice to Latinos in Milwaukee. Finally, Time can be defined as any

influence that the individual can experience at any given time. Of course, researchers can demarcate important events or patterns that are relevant to whatever was being discussed, but really each day that an individual lives and exists, up to death, falls under the definition of Time. In this study, Time described the process that individuals experience from the moment of learning about the study up to any result that occurred, such as calling to ask or not call. Similarly, the individuals' life experiences, for instance, prior to being infected with HIV and after being infected with HIV were critical., the various symptoms, thoughts, or values about HIV can change across a given time and with current events. In the context of this dissertation, the researcher examined the components that could have influenced the participants in the study; specifically, he wanted to determine the factors that influenced retention and in the collection of complete data.

As part of the SNR model, acquiring previous history is important through a clinical interview. Since this was not always possible in this study, the literature was consulted frequently. In the following paragraphs the context of the study will be discussed as part of the PPCT study because it allows the flexibility to incorporate all relevant components. Furthermore, the person, process, and time discussions will be covered later as part of the individual system discussions. Thus, the researcher will first discuss the challenges that he faced with the study that influenced the adaptation of the dissertation into a case study.

A Post-Hoc Interpretation of the Context

Given that Bronfenbrenner's theory is contingent on the context in which the study was taking place, the researcher will summarize the difficulties recruiting since the study received IRB approval. Initially, there were difficulties recruiting participants as the researcher received

phone calls from individuals who did not meet all criteria to participate. For instance, some patients had psychological and psychiatric symptoms that have been known to be related to abnormal brain function, such as visual and auditory hallucinations, and that could also be related to serious undiagnosed psychiatric syndromes. The literature consistently showed that HIV infection was highly comorbid with many psychological, psychiatric, and somatic conditions that could also affect brain function (Alciati et al., 2001; Sall et al., 2009), and thus these are features that are characteristic and should be expected in a sample of patients with HIV. The exclusion of participants with hallucinations carries over from the study with healthy individuals. This exclusionary criterion was not necessary given the high comorbidity in this patient population. However, experiencing hallucinations in general during testing could be disruptive to data acquisition. Typically, the research studies in which the researcher has collaborated typically excluded individuals who experienced this disturbance even if it is normative if there was risk that data collection could be hindered.

In thinking about the context of this study, the researcher acknowledged that even given all the comorbidities associated with HIV, the dissertation was designed to recruit generally healthy patients who had undetectable viral loads and minimal to moderate psychiatric symptoms. Operationally, this would describe a patient who was adherent to their medications, attends medical appointments, and had an undetectable viral load, as the SSC clinic allowed me to access patients who were also participants in a program that monitored their progress. Considering Bronfenbrenner's model as well as the literature on many high-functioning populations of people living with HIV, the researcher described and expected to work with individuals who had adequate access to resources and a moderate level of education. Had the researcher completed clinical experience with Latino patients as he is gaining on internship, he

would have known that the sample would likely have more health problems and reported more severe psychiatric symptoms than anticipated. Eventually however, there were difficulties recruiting in general, as potential participant inquiries about the study discontinued. When the study began having recruitment difficulties, several attempts were made to improve recruitment including attending several events, being available during clinic visits, posting fliers in the clinic, and they all ultimately failed. Somehow, the researcher was unable to elicit interest in the pool of potential participants.

A Review of Original Study

The purpose of the original study was to examine the relationships among neurocognition and medication adherence in monolingual Spanish-speaking patients living with HIV. This is a population that has been underrepresented in the neuropsychological literature, although this population has recently received more attention (Lopez et al., 2017; Miranda et al., 2016). Researchers have examined whether cognitive abilities are related to medication nonadherence in patients living with HIV (Andrade et al., 2012). the goal was to replicate and extend the extant literature with a strictly monolingual sample. Specifically, the literature suggests that memory and executive functions are the most imperative in adequate medication adherence and the aim was to determine if this was the case in the current sample (Woods et al., 2008). Typically, individuals with memory and executive functioning difficulties are less adherent to their HIV treatment medication (Woods et al., 2011). However, recruitment and enrollment for this project stalled after one year and the researcher was unable to recruit enough participants to collect enough data to adequately answer the dissertation research questions. Furthermore, the investigator observed problems with the validity of some data that were collected, and he wanted

to understand if there was empirical evidence for the data variations. Therefore, after consultation with his advisor and committee members, focus of the study evolved.

For the current project, the investigator reframed the dissertation as a case study and conducted a post-hoc interpretation of the evidence that might explain why there were difficulties in both recruiting and obtaining valid data for this study. Specifically, the researcher chose to use Bronfenbrenner's Ecological Systems Model to examine the various relationships across system levels that could have (1) contributed to the difficulties that were experienced recruiting participants and (2) contributed to the challenges that were experienced collecting complete and valid data from participants who did enroll. The researcher used Bronfenbrenner's theory to conduct an exploration of the various ecological systems with which potential participants and enrolled participants were both directly and indirectly involved. Though initially used as a developmental framework for pediatric studies, the investigator adapted Bronfenbrenner's model to examine participants as the unit of interpretation of the case study and discuss the various relationships that could have influenced the results of the study. Moreover, the researcher will use the results of the study as an opportunity to describe the challenges and to develop a comprehensive list of suggestions for best practices.

The Development of the Case Study

The purpose of the process evaluation case study was to determine the reasons why the study was not successful in recruiting and enrolling participants. This approach was selected by the researcher because it enabled the exploration and description of the context in which the study took place, all the relevant factors that influenced recruitment, incorporate the clinical and research experiences of the researcher, and allow the specific analysis of the neuropsychological

data. Bronfenbrenner's model has been applied to qualitative investigations about acculturation and stress in Chinese students (Bhowmik, et al., 2018), a pilot study of an intervention for teacher with students who have attention problems (De Jongh et al., 2019), and a quantitative study of hepatitis B and C in patients in China (Ren et al., 2017). Thus, it provided the flexibility to discuss relevant findings and the researcher found similarities with a model that he used clinically, the SRN framework discussed previously. Given the inclusion of neuropsychological data, the researcher was influenced by both Bronfenbrenner's model and further used the SRN framework to further conceptualize and describe by findings post hoc (Suarez et al., under review). Bronfenbrenner's Ecological systems theory was used to evaluate the data at the microsystem, mesosystem, and macrosystem levels. For the discussion, the researcher described how the findings fit within the process-center-context-time framework and answer the following questions: Why were there difficulties recruiting participants? What were some of the factors that influenced patient participation? Why did participants have difficulties completing the study session? What were the factors that contributed to non-completion? Neuropsychological studies that examined monolingual Spanish-speaking patients were still lacking in the literature (Andrade et al., 2012; Lopez et al., 2017; Miranda et al., 2016). Also, reports have not been published where researchers detail failed studies or difficulties with monolingual Spanish-speaking Latinos in general. Further, dissertations with similar themes have also not been found. Thus, the aim was to describe and analyze this experience to aid forthcoming studies with monolingual Spanish-speaking Latinos.

Proximal Processes, Demographic Variables, and Neuropsychological Data

Bronfenbrenner described proximal processes as the most powerful predictor of human development. Proximal processes are elements that are involved in reciprocal interaction between the individual and other important contextual persons, objects, symbols, in their immediate environment (Bronfenbrenner, 1995). These processes can be interactions with individuals, structural inequalities, cultural values, psychological factors, emotions, political affiliations, cognitions, and even historical facts. In this study, it was essential to examine proximal processes by first analyzing and describing demographic information about the participant pool. An exploration of the demographic participant data revealed that all participants were of Puerto Rican or Mexican descent. From the entire sample of 17, only one individual reported having been raised in the United States, meaning that the other participants migrated from their country of birth to the United States. This was important because it suggested that most of the findings were descriptive of immigrants who were raised and educated outside of the United States and does capture a demographic that was not typically captured in HIV and memory research. Participants were also living close to the poverty line, as all had incomes lower than \$800 a month. The level of education varied from elementary school to college levels in the sample which highlights evidence of heterogeneity despite all participants having been Latino, low-income, migrants in middle to late adulthood. That individuals with college-level education were receiving care at a government clinic due to living under the poverty line was important but also suggests that quality of education was important and should be explored more thoroughly if researchers were interested in recruiting individuals from ambiguous educational levels. For instance, when participants report having a high school education from a different country, it was still important to understand the curricula and not presume that their education

system was like that of the United States. Overall, these findings confirm that the proximal processes that were explored were of migrant, lower-income individuals with varying levels of education who are living with HIV. Specifically, it was important to highlight the importance and need to consider quality of education and access to educational resources when determining level of literacy for participants especially when the aim was to recruit immigrants who were not educated in the United States.

Although the participants were immigrants who were educated outside the United States, the researcher expected that performing neuropsychological tests would yield results that were reflective of their level of respectively reported education and experiences. When the tests were being selected, the aim was to find tests that were sensitive to the needs of non-English speakers and writers, and preliterate or subliterate individuals. For this exploration, the researcher examined proximal processes outside of participants' direct control (e.g., having been born in another country, legal status, gender, race, ethnicity), and in testing for the study were different than that of participant from previous studies. Although the investigator attempted to find measures that were culturally appropriate, the participants still had unique patterns on the tests that were remarkable. Next, behavioral observations or patterns of data will be discussed that could explain the proximal processes that participants experienced when the researcher was administering tests.

The neuropsychological findings revealed that participants understood the instructions and were able to produce scorable data on a verbal learning measure that was administered. In contrast, participants had challenges understanding the instructions and producing scorable data on a visual memory test. For instance, it appeared that owing to cultural context, some individuals had not been predisposed to copying or drawing figures and other participants were

not able to reproduce figures during immediate and delay recall trials. However, participants did recognize the figures, which suggested that reproduction deficits in recall trials were not due purely to memory impairments; instead, it could have been due to visuospatial abilities, medical factors such as cardiovascular health and HIV disease, and psychiatric factors such as anxiety. As previously discussed, HIV infection was associated with deficits in motor functions, memory, and executive functions. Untreated cardiovascular disease can lead to difficulties in recalling memory, confusing foils in recognition memory, slowness of speed of thinking, and variability in attention. Anxiety specific, has similar neuropsychological effects to that of untreated cardiovascular disease. Thus, the difficulties observed on this test were most likely due to true neurological deficits, proximal processes, rather than variability in effort.

The computerized tasks also produced difficulties for participants. The tasks rely heavily on memory and require participants to make visual discriminations by pressing keys with their fingers. All participants who attempted the computerized tests completed at least one of the required categories, which suggested that participants understood the test instructions. However, the data could be interpreted as possible random answering. Since there were only two options in each discrimination, there was always a 50% chance of selecting the correct discrimination, so unless the participants meet the required trials to criterion, the data may seem random. Therefore, given that participants were able to recognize visual information on a non-computerized test then the researcher used this as evidence that these challenges were not necessarily due to pure memory deficits. Of course, the parameters only allowed up to 500 trials to complete the tasks, it is unknown how many trials it would take a participant to discover the pattern other than it was likely more than 500. Therefore, these types of tests might be useful for patients in circumstances in which typical paper-pencil testing was not appropriate. However, given the difficulties in

understanding instructions and the amount of trials that are probably necessary to capture adequate performance, these tests were not appropriate for this sample.

The Berg's card sorting test was the measure participants had the most difficulty completing. Participants were routinely confused by the lack of instructions since this task was designed to provide limited direction and allow the patient/participant to resolve. Importantly, providing too much instruction would invalidate the test. The neuropsychological data were examined, given the amount of perseverative errors that were committed by participants, and the number of participants who only completed one category, it cannot be ruled out that participants had difficulties understanding instructions. Further, some participants had one to four failures to maintain set, which was a type of error unique to the card sorting test. This error describes that the individual was following a specific correct pattern, but suddenly made an incorrect response, likely due to inattention, confusion, or memory difficulties, that then interrupted the continuous 10 correct answers necessary to move on to the next category. The data also revealed that participants, in general, committed many perseverative errors, which indicates that participants kept utilizing a previously correct rule to sort the cards instead of adjusting and establishing a new rule. Clinically, this can occur for several reasons, which could include typical HIV clinical pathology and even malingering or random answering. However, given that the neuroscientific literature about HIV diseases consistently cites executive functioning difficulties in patients with undetectable HIV loads (compared to seronegative controls and patients with detectable HIV loads) it is most probable that the difficulties observed were due to true impairments in this domain (Dawes et al., 2008; Reger et al., 2002, Reger et al., 2005). However, the difficulty would lie in determining the etiology of the impairments and if there was something else besides HIV, though this was beyond the scope of the exploration.

Although the measures used in this study have been used at research universities with clinical and typically-developing populations who were English speaking, as far as the researcher is aware, he is the first person to use it in a culturally and linguistically different group. Therefore, the findings discussed could be important for both clinical and research settings, especially working with disadvantaged populations from different cultures, with lower literacy and limited exposure to research. Specifically, the findings indicate that certain types of tests might not be as useful in use within samples similar to the one that participated in the study. For example, when the researcher was programming the transverse patterning task, he wanted to ensure that he was able to distinguish between true memory deficits and inattention in healthy young adults who were currently enrolled in college and older adults who all had at least a bachelor's degree. Thus, he made sure that it was as difficult as it could be in contrast to the approach others have taken to make the task as simple as possible to ensure that older adults can complete it (Driscoll, et al., 2003). Given that participants had difficulty completing this task, the researcher concludes that he should have undertaken more piloting of the instrument within this specific population. In contrast, the researcher obtained scorable data for the BVMT, HVLIT, and Berg's card sorting test, leading him to conclude that they are likely adequate for clinical purposes given that norms that correct for cultural and linguistic factors exist. However, for research purposes, other measures beside the BVMT and Berg's card sorting test should be administered. In clinical work, a score of 0 is understood in the context of the patient and their medical history. A score of 0 in a research study that requires variance and quantitative figures to make group comparisons was not adequate, unless of course we were discussing single participants at a time. These findings stand as evidence that the corrections provided by Cherner

and colleagues (2007) are well-normed tests to use with clinical populations in clinical and some research settings.

In summary, there were some events that influenced the results of the dissertation that serve as relevant proximal processes for the participants when using the process-person-context-time approach. First, the dissertation was developed after piloting in a substantially different sample with the objective of comparing groups (seronegative young adults, seronegative older adults, HIV adult patients). The process of testing, which proved to be more efficient for individuals who easily understand basic instructions and need minimal scaffolding, was significantly different for the dissertation sample that represents a population that is historically underrepresented in the literature. Thus, the process of writing this dissertation in the aim of obtaining a PhD in Clinical Psychology was the context and time in which the participants were recruited. Clinically and professionally, the researcher acquired clinical training on internship that influenced the adaptation of Bronfenbrenner's model to a case study. The researcher's background in the SRN model and its similarities with the ecological model, allowed for an interpretation that may not have been possible without this combined training. Therefore, the researcher was prepared to recognize relevant behavioral observations or data patterns that were standard to this population, which related to the process and person elements of the Bronfenbrenner's model. Finally, the researcher detailed important observations on the neuropsychological tests that gave a glimpse of the proximal processes that occurred during the study session. The investigator addressed notable patterns and behaviors and compared those elements with the experiences he may have had as he developed clinical skills. In the following paragraphs, the qualitative findings of the dissertation in the context of the Bronfenbrenner's Ecological Theory will be discussed.

Qualitative Interpretations

For the second part of the discussion, the findings were stratified and described in the context of the microsystem, the mesosystem, and the macrosystem. The findings section was organized by system level to offer the reader a bottom-up lens of the contributors to the findings in the dissertation. As part of this application, actors were identified in each system and examined their relationships to best understand what was occurring at each specific level that could have affected study recruitment and data completion. This post-hoc exploration revealed individual, social, cultural, and political factors that could have contributed to the difficulties that were experienced with recruitment and collection of usable data. However, it is important to note that the interpretation of the different systems was embedded within the PPCT model. At times all will be referenced, but there were some relationships that were only specific to an element or two.

Proximal Processes in the Microsystem

Compared to the other systems, the discussion of the microsystem was the most expansive and included more actors that significantly contributed to recruitment and data collection difficulties. For example, the relationship between participants and the neuropsychological tests was of utmost importance since this quantitative data was necessary to conduct the statistical analyses. Furthermore, the relationship between participant and neuropsychological tests was one that the researcher also experienced and thus consisted of proximal processes were witnessed first-hand. The findings suggested that some of the measures that the researcher used in other studies were not adequately piloted for use in a culturally different participant pool with whom the researcher had never work with in a professional

setting. Specifically, the MMAA was too challenging, and though it was familiar to the researcher and provides valuable cognitive information about the patient, it was structured behind a pharmaceutical regimen that was more difficult than the ones the current patients had. It required a higher level of organization that was particularly difficult because it had to be done without any cognitive strategies that most people use (writing things down, repetition, reading slowly, etc). Alas, it appeared that this test, though intellectually interesting, lacked adequate external validity to be used with a patient population like the one for this dissertation.

Additionally, a computerized card-sorting test appeared to be the most difficult to participants, though normally this could provide important information in a clinical setting. These difficulties are being discussed from the perspective of a researcher, though the writer is also familiar with the clinical view. Clinicians interpret data that would cloud a statistical effect in a research study, as would have been the case with mine had the researcher accomplished his recruitment goal. Therefore, the card-sorting test was an appropriate clinical and research tool that had been widely used by researchers and clinicians. Regarding the use of any experimental computerized task, the findings suggest that the investigators should have piloted the test with the population being investigated prior to officially recruiting. When a population of interest is difficult to recruit, researchers wish to utilize the fewest number of them for simply piloting the instruments. However, piloting a task with sample of interest will prevent completion difficulties like the ones that were experienced in this study and also allow the researcher to adjust the task parameters. For example, in hindsight, after participants did not respond to the task as planned with two participants the task parameters should have adapted to that of other studies who had more generous thresholds (Driscoll et al., 2003).

Another component of the microsystem involved the case manager and participant, both proximal processes and interactions that the researcher did not witness. In the interpretation, the case manager and participant relationship were particularly important because it was the very first time that a participant learned about the research study and it was also the most used avenue for recruitment. Specifically, a case worker who managed the cases of patients who were identified as being at low risk for treatment nonadherence was the person who was helping with the recruitment of participants. She offered to tell suitable patients about the study and encourage them to enroll. The relationship between the researcher and the SSC had also evolved from initial conversations in 2015 until the conclusion of the recruitment process in 2017. As part of this post hoc interpretation, the context and process over time were important to consider within the Bronfenbrenner model, as they were important proximal processes that indirectly influenced participants because they were patients at SSC. Also, the method of delivery and disposition of the individual who disbursed the study information were important because it affected whether a patient decided to call or not. For instance, if the case workers presented the information with enthusiasm versus with irritation could affect the likelihood that a patient called to be screened and is thus a significant proximal process to consider. Given that recruitment relied on this person so heavily, it would have been important for her to receive training and a standardized script for recruitment.

The relationship between the participant and the researcher was also evaluated since participants spent most of their time interacting with them. Patients heard about the investigator from their case workers, then spoke with him on the phone for the screening procedure, and finally, they completed (or not) the study session that he was hosting. For the screening procedure, the findings revealed that participants could have felt uncomfortable or anxious about

the questions he was asking. Since the investigator has been in the psychological sciences field for over a decade now, speaking about certain topics has become commonplace. However, this comfort in discussing sensitive topics such as drug use and HIV infection could be more difficult for others, especially if they were concealing this information for a personal reason. Curiously, some individuals met criteria for the study at the screening process, but then reported additional psychological and neurological symptoms that were far more severe than reported during the interview and that disqualified the participant. This could have occurred for several reasons, one of them being that the screening tool does not include detailed questions that would have prompted detailed answers. Since the study was designed such that the participants should have been able to complete many tasks in a small amount of time, the investigator did not include more detailed measures, once again, revealing the context and process of research and dissertation. Instead, the questions were framed generally, and it was possible that the participants did not realize that some of their experiences were included under a bigger umbrella. In a similar vein, some patients reported using substances during the phone screening and then attended the study session under the influence of a mood-altering substance that would not allow them to complete the study session successfully. In this case, the study session was terminated, and participants were encouraged to return later, but none of these participants returned. Although they flowed naturally, this interaction could have been interpreted as awkward as the session was terminated suddenly. The proximal processes between participant and researcher were extensive, and this could have led to a fraction in the researcher-participant alliance. When participants were scheduled they were specifically told by the investigator to refrain from using any mind-altering substances. In this case, there was very little the researcher could do to prevent participants from using substances before a study session, as those were proximal processes that

only the individual can control. Thus, it was important to take this into account and assess the likelihood that this might happen with the population of interest. In general, the screening procedure was designed specifically to be brief, but in that brevity some important information went unlearned. Therefore, screening procedures should be more thorough to prevent these challenges and to trim down the study session as much of the information would overlap. In summary, it was important to reiterate the PhD dissertation context in which the participants were recruited and tested, as it holds the proximal processes that influenced the outcome of this dissertation. If the circumstances had been more optimal and resources had been more readily available, the results could have been different.

The researcher is an educated, seronegative, Gay man, and the in the findings he described the different ways in which he could have indirectly influenced participant behavior. In detail, he discussed the ways in which his identity as a gay man, as an educated person, and as a seronegative person affected participant recruitment and data collection. Though unlikely, the researcher examined cultural elements that were pertinent. For instance, his status as an educated person could have intimidated participants, but instead the findings suggest that it was comforting to them that the researcher appeared well-prepared and professional. The investigator's status as a Gay man could have ignited homophobic emotions, but in general the findings do not support this. Lastly, there exists continued stigma about HIV and Gay men. Culturally, it might be difficult for non-Gay men to be associated with HIV studies because it could out them. Although a possibility, the findings did not find that these elements served as actors in the difficulties with recruitment and data collection.

The exploration also revealed that perhaps certain patients who were previously excluded should not have been. For example, visual hallucinations are common in HIV disease and they

are not necessarily related to psychiatric factors (Alciati et al., 2001). Some patients with HIV have reported seeing hallucinations when they were waking up or when they were falling asleep, outside of the context of psychiatric disorders as was often seen in psychotic conditions. Since these symptoms appeared to be common, if it does not impede on neuropsychological tests, then these patients should be enrolled in the study. Similarly, there appears to be a relationship with learning disabilities and susceptibility to engaging in activities that could lead to HIV infection. Learning disabilities or academic problems that could have confounded the neurocognitive results were reported by some participants. In hindsight, the study was adequately designed to recruit individuals with at least a high school education who also had access to transportation and whose daily lives would not be adversely affected. At that time, the investigator did not realize the extent to which the availability of resources and educational background might influenced the success with recruitment and testing. For instance, in the clinical setting providers generally schedule more testing hours for patients who are not English-speaking and who have a history of less access to resources. Typically, these patients tend to be slower, require more direct instruction, and have less stamina to endure longer testing days endurance (Ochsner, 2003; Pozniak et al., 2014). Providers have the benefit of scheduling second and third days of testing as required by their treatment plan, but in the research setting, the two-hour sessions were firm and the researcher did not have the funding to schedule more study sessions. Some participants had difficulties understanding the instructions to the tests or surveys, required more directive attention than was possible within a two-hour time frame, and a result did not complete all test items. It was presumptuous to assume that both populations would complete tasks at a similar rate, and it might have been prudent to add a paid hour to each study session to ensure ample time to complete all the tasks. Even so, participant fatigue might have negated the usefulness of

adding additional time onto the study session. In summary, the findings revealed that hallucinations and learning disabilities might compose common symptoms often seen in people with HIV that might also cause additional fatigue or strain. Thus, individuals with visual hallucinations and learning disabilities should not be excluded unless they directly hinder study participation.

Proximal Processes in the Mesosystem

Bronfenbrenner described how human development involves a relationship among biological and psychological traits and their environments (Rosa and Tudge, 2013). Within these environments, the proximal processes begin adapting as the individual progresses and develops. With this dissertation, participants were exposed to UWM as the researcher's training and affiliation was to UWM and not SSC. Therefore, it was important to examine the proximal processes that the investigator indirectly brought into the participant's lives simply by being affiliated with both SSC and UWM. It was also important to examine the interactions and planning that occurred before participants were recruited, as this is an example of an indirect influence.

The mesosystem is the second level of Bronfenbrenner's Ecological systems theory which consists of interactions between actors in two individual microsystems in which the individual is a member. Bronfenbrenner thought that an individual is actively engaged with, affected, and socialized by other objects in their microsystem. In reference to the PPCT model and the context of this study, the two microsystems that were described in the post-hoc mesosystem interpretation were UWM and SSC. Specifically, the relationships between the researcher at UWM and the SSC colleagues. Before participants were recruited, colleagues from UWM and

SSC were planning this study in collaboration. Thus, participants were indirectly affected by two microsystems and actors. Technically, participants had interactions with UWM through their recruitment for the research study. Further, they have more interactions with the SSC because many participants receive all their healthcare through this institution.

The findings focused on the professional relationship between actors at UWM and SSC before recruitment started. The researcher examined the proximal processes that occurred in the planning and development of the study. This interpretation falls under the mesosystem and serves as an example of indirect influence on an individual, as access to these potential participants was convenient because they were existing actors in a microsystem that they shared with the researcher. Specifically, it was the researcher's desire to expand the neuroscientific literature that commenced his interactions with SSC. At the meetings, the professional values and goals of both institutions enabled the development and execution of the study. Together, these findings can be described as proximal processes within a professional context, as the researcher served as a bridge between UWM and SSC.

Proximal Processes in the Exosystem

The third level of Bronfenbrenner's ecological systems model is the Exosystem, which comprises of proximal processes that can influence an individual indirectly. These proximal processes indirectly serve as an actor that influences thoughts and behaviors. For this part of the discussion, the actors that influenced the participant unbeknown to them. Specifically, the findings focused on the professional relationship between the SSC and UWM, and of aspects of the researcher's identity that could have influenced the findings.

As previously mentioned, recruitment for this study relied on the relationships between the researcher and the case worker, and by default, the SSC, UWM, and the exosystem. After all, the clinic agreed to become involved in the project because they believed in the research question and wanted to participate in the professional development of the researcher. In the interpretation it was impossible to determine if there were political reasons that influenced the clinic's decision to help the investigator recruit, but there were probably some cultural factors that served as influences, as the director and case workers are LGBT and Latino. Relatedly, given that social media is easy to access worldwide it would have been a great resource to recruit participants, even if not through the SSC. Additionally, this would have offered an opportunity for interested individuals to fill out an online survey and provide preliminary questions that could help us determine who was eligible. Another strategy could have been to include another microsystem to aid us in collecting data, such as the AIDS Resource Center of Wisconsin (ARCW). However, the researcher approached the ARCW several times and was unable to establish a professional relationship with them.

Proximal Processes in the Macrosystem

The macrosystem was the final level of Bronfenbrenner's Ecological systems theory that was pertinent to the interpretation. This level consists of proximal processes that contain cultural, social, and political elements that indirectly affect an individual. This portion of the exploration focused largely on an applied secondary interpretation of the existent literature and current events. For much of the discussion of the actors in the macrosystem, there existed little direct evidence that supports that these proximal processes influenced recruitment for the study. However, this was often the case for studies since it was difficult to measure something external

that is not a main focus but that one might be aware affects individuals in this particular population of interest. Some of the features I discussed were immigration status and structural barriers to research participation.

The vast majority of the participants in the study were immigrants, some of whom might have been unauthorized. Latinos who are in the country without authorization fear deportation, and the family members of unauthorized individuals also fear their deportation. The fear of deportation is common in Latino culture, and the researcher also experienced fear of deportation of his family members and patients. In the study there was no direct formal question made to participants about immigration status. Rather, the researcher asked participants if they go back to Mexico to visit, and that provided an indirect answer to the question. For instance, participants would say they could not leave the country and return easily. Similarly, recruitment started during the 2016 primary and general elections, and thus a topic of conversation were often the negative remarks against Latinos, especially Mexicans, in the United States. From the researcher's interactions with participants, those who were unauthorized to be in this country feared deportation. However, this fear was healthy and realistic, as there was a possibility that they could be deported. Everyone indicated that they felt safe at SSC because there had never been any deportation incidents there; this was the main reason the researcher decided to hold study session there. In conclusion, the researcher discussed the social and cultural elements that affected recruitment for the study and it was important to consider that individuals from the studied population did not always feel protected in this country, and that could have affected recruitment.

When the qualitative data were reviewed, the most striking finding from the exploration was the underdeveloped relationship between SSC and UWM Department of Psychology in

general. The HIV clinic specifically had never had any contact with UWM Psychology in any professional setting. In fact, the director reported that their only knowledge of a collaboration between SSC and UWM Psychology existed when one of our psychology students was completing a therapy rotation in their mental health clinic in 2015-2016. Similarly, when each participant was asked about their knowledge of UWM, most acknowledged their existence but reported no direct relation to the institution. Therefore, it was necessary to examine how the perception of education and institutions influenced recruitment and participation.

All participants in the study were migrants from other countries who were educated under different circumstances. Individuals who migrated to the United States from Spanish-speaking countries know the importance of education, and typically feel admiration toward students and professionals who completed their degrees (Williams et al., 2004). Often, higher education is associated with prestige, intelligence, and money, since it is expected that college-level persons have higher paying jobs. Thus, here and in any other country, exposure to universities is very minimal and individuals with lower levels of education could become uncomfortable when visiting these institutions. Furthermore, the literature suggests that Latinos have a general mistrust for research and medical institutions, especially when the persons working with them do not speak their language or understand their culture (Levkoff and Sanchez, 2003). Individuals in general have mistrust for anything they were not familiar with, even, so the lack of access and familiarity to UWM is something that could have intimidated and deterred potential participants. Also, the stigma associated with having HIV and the potential of accidentally divulging their stigmatized and private diagnosis offer enough reasons to deter anyone from participating or becoming associated. Anecdotally, the reason there is fear and mistrust of institutions is because there are few existing relationships between the universities and patient communities. Until

recent years, few neuropsychological studies were aimed at investigating minority populations. Though, this relationship goes beyond the scope of the study, the best way to bridge the gap between institution and communities is to establish and maintain a healthy relationship. By becoming more visible to the communities more opportunities become available to have direct interactions hopes that they open, enroll, and participate in the research study.

Access to this unique population also presented some disadvantages in recruitment that were consistent with some challenges that have been cited in the literature. These factors have been found to impede recruitment to research study, and they include education, transportation, confidentiality, stigma, and social class which are indirect influences in the macrosystem. Transportation was often a barrier that affected participants. Preferably, and ideally, the researchers would have preferred that all participants come to UWM to complete testing. Instead, each participant elected to meet at SSC because it was a short walk or brief bus ride away as most lived on the South side of Milwaukee. Therefore, the investigator had to transport the materials from UWM to SSC each time. General fear of revealing HIV status was something some participants worried about due to the societal stigma that was associated with being HIV positive. Especially in smaller communities from disadvantaged Latino backgrounds there still exists stigma about HIV and its infectious effects. Prior to meeting with participants, the researcher did not consider how research study sessions affected the daily schedule of participants. The researcher did not entertain that participants would have to miss work or other responsibilities to attend the study session. Instead, he assumed that patients would be eager to participate in the study because it paid a modest \$30. Although participants appeared to enjoy the research experience, the \$30 cash payment was likely not sufficient to offset how it affected their daily lives. For example, some participants reported difficulties in finding child care to attend the

study session, though the researcher is unsure of how the payment factored into their decision. It is also important to remember that all participants came from a low-cost clinic meaning that all participants lived below the poverty level. The study session was also taking place during business hours, and elements that would prevent or aid individuals in attending study sessions were analyzed. The findings revealed that it was probably difficult for individuals with stricter jobs who worked during business hours and less flexible careers to miss from work to participate. This meant that most participants were unemployed or employed during the second and third shifts. When evening appointments were offered, the researcher learned that public transportation to the east side of Milwaukee may feel complicated and unsafe, which may have attenuated their comfort in attending study sessions there. When house visits were offered, participants indicated that privacy was an issue. The difficulties discussed can be attributed to structural social and economic factors that place certain members of our communities at a disadvantage regarding access to resources and wealth. Therefore, this interpretation qualifies to be included in the macrosystem discussion because the actors were intangible and indirectly affect the individuals in his/her microsystem.

In this section, the quantitative and qualitative findings were discussed, and the researcher explained how they were related to the difficulties with recruitment and gathering complete data. The findings were described through the lens of the different levels of the Bronfenbrenner model and highlighted remarkable proximal processes that were influential. Next, the current literature on research recruitment and retention with Latino and minority populations will be discussed in relation to whether this body of literature is consistent with the current study's findings. The discussion will conclude by describing the study's limitations and

providing recommendations for best practices when working with culturally different populations in research contexts.

Study Contributions to the literature on Latino Recruitment

The literature on research recruitment with Latinos was reviewed to determine if the difficulties with recruitment and data collection for this study were like what was already in the literature or if this was a different phenomenon. Several reports have been published where researchers detailed their difficulties recruiting Latinos for their research purposes (Larson et al., 2009). Larson and colleagues reported that written flyers were not effective and the best method to recruit was through word of mouth and video announcements. Written flyers were not effective for this study as not a single participant reported being recruited from the fliers in the clinic. Instead, word of mouth was most effective because all participants were referred by the case worker. This showed that a level of familiarity and trust was necessary to recruit participants from this population. However, it is important to consider that some participants had difficulties due to technological limitations. For instance, some participants indicated that they did not have adequate access to the internet, computers, or smart phones to communicate. Some participants called me from the clinic because they did not have another way to communicate with me. Initially, they were asked if it was because of issues of privacy, but two individuals indicated that this was their only method of communication other than pay phones. This suggested that some patients were virtually unreachable as the only point of communication existed at SSC. It was likely, however, that this becomes less and less the case given the current easier access to cell phones, computers, and other technology with government programs and the effectiveness of social media in advertisement effectiveness (Harris et al., 2019).

Some influences that were relevant to the study because they also serve as barriers to participant in Latinos that have been identified by researchers were perceived lack of access of information, fatigue, competing demands that conflicted with research, fear of unintended outcomes, stigma, and legal status (George et al., 2014; Rodriguez et al., 2013; Waheed et al., 2015). In hindsight, patients who were interested in our study did have some difficulties with competing demands, especially as participants struggled to miss work, find transportation, or find child care to attend the session. These challenges should have been carefully considered especially when recruiting from disadvantaged areas and poorer populations. Nonetheless, there is no evidence that fatigue, stigma, fear, or legal status affected performance. The researcher did receive questions about how patient confidentiality would be carried out in the study. In this case, the participant was concerned that the university would have access to his medical file and they were assured this was not the case. Most participants the investigator spoke to reported feeling more comfortable if the study sessions occurred at SSC because they had already established access to transportation there and it was a safe and familiar place to them. This suggested that participants had thoughts about confidentiality and fear that could reflect why some patients elected to not participate.

Levkoff and Sanchez (2003) suggested that recruitment and retention success occurred when there was a match between the goals of the ethnic minority communities and the research community. Further, recognizing and understanding the culture of each ethnic minority community as well the research perspectives is essential to successful recruitment and retention of ethnic minority elderly individuals (Levkoff and Sanchez, 2003). For example, minority participants (Black and Latinos) reported that study personnel were unkind to them and it led to attrition (Castillo-Mancilla et al., 2014). This occurred despite a fair reward for participation

which indicates that self-comfort and respect play a big role in recruitment and retention of Latino participants. Finally, Levison et al., 2017 proposed six themes that were perceived to influence HIV clinic attendance: (1) stigma as a barrier to HIV serostatus disclosure; (2) social support as a safety net during negative life circumstances; (3) unaddressed trauma and substance use leading to interruption in care; (4) a trusting relationship between patient and provider motivating HIV clinic attendance; (5) basic unmet needs competing with the perceived value of HIV care; and (6) religion providing a source of hope and optimism. Cultural subthemes were the centrality of family (familismo), masculinity (machismo), and trusting relationships (confianza; Levison et al., 2017). Although the previously cited study was in the context of gaining services in a clinic the results can be applied to research studies as well. Creating an environment that was in accordance with the cultural and social proximal processes of the individual was important for recruitment, retention, and the collection of valid data.

Considerations for neuropsychological studies and general research with Latinos.

Though this dissertation can be perceived as unsuccessful because the investigator was unable to answer the research questions initially set forth, he has a unique opportunity to examine the underpinnings and mechanics of the study and offer considerations for conducting research and recruitment with this population. The goal was to increase Latino participation in psychological research, and as he has discussed, this might likely only be accomplished if an environment and strategy are created to fit the cultural and social values of this group. Second, it was necessary to develop culturally sensitive tests with adequate norms for use in clinical and research settings alike. This will ensure that research findings were more valid, and that fewer patients were misdiagnosed in clinical settings. The investigator also wanted to expand on the

importance of receiving health care and conducting studies in the study group's dominant language. This was the single best way to develop trust and rapport with your group of interest.

Considerations for Future Studies Based Upon the Current Findings

Sample Considerations:

In hindsight, given the barriers to participation that the researcher has described (e.g., patient intoxication at the time of the interview) and difficulties with participation that some members of the sample had, it appears that there was an overestimation of the size of the participant pool that was needed in order to adequately complete the aims of the initial study. Also, visual hallucinations were a large part of why some patients were excluded from this study. However, visual hallucinations appear to be a common proximal process with HIV infection that are due to brain changes rather than organic psychosis (Alciati et al, 2001). In future HIV investigations researchers should not exclude patients who experience visual hallucinations if they are not present at the time of the interview and if they do not occur in the context of another major mental illness, such as schizophrenia. Finally, individuals with learning disabilities should not be excluded from participating because of the evidence that people with a learning disability were at risk of becoming infected with HIV, and thus HIV patients might be more likely to have a learning disability (Rohleder and Swartz, 2009). Depending on the type of learning disability that was diagnosed, researchers could anticipate difficulties with memory and executive function tests. Specifically, challenges with word-learning tests and the card sorting mental flexibility tests. Importantly, the neurocognitive literature was clear that even among patients with HIV who have undetectable viral loads, deficits in

memory and executive functioning tests compared to HIV- controls are common (Watkins & Treusman, 2015). It was unknown how HIV deficits interact with a learning disability, and this is something that can be further explored as adding these patients will lead to difficulties in determining the etiology of specific deficits that are of research interest to investigators. This sample, however, would be closer the true demographic and experience of the patient population, and thus provides additional external validity.

Screening Considerations

Evaluating the screening procedure used to determine eligibility has also provided an opportunity to also learn about the needs of participants to ensure the successful completion of the study session. Researchers would benefit from making it standard to ask questions about hearing and vision to determine if patients were adequately able to hear and see testing stimuli. If not, they must have seeing and hearing accommodations to offer participants. For instance, in this study, the researcher provided inexpensive reading glasses available to participants. For the more technically savvy individuals, researchers could also create a website where patients can independently and privately go through the screening procedure. This would allow participants to respond to questions in their own terms in hopes of obtaining more valid and truthful information.

Suggestions for best practices

Through this dissertation experience, the researcher gathered important qualitative data that were necessary to consider when working with certain populations. It is important to mold the research context to fit within what was expected culturally from the research population. This

would likely improve level of comfort and thus retention and recruitment. Within this context, he provides the following recommendations. First, the investigator will present the practices that he implemented in his original research study and that are important to continue doing:

(A) Information for the culturally naïve individual working with this population—that includes practices the researcher implemented, and thinks are important.

1. Hire staff that speak the language of your population of interest.
2. Examine the social and cultural considerations for the patient population of interest. Learn about their value system, needs in the community, social practices, beliefs about research and medical care.
3. Provide listening devices and glasses for participants who need help with seeing and hearing.
4. Be clear about expectations regarding substance use. With the legalization of certain substances, more individuals are using substances that could impair cognition.
5. Have accommodations for individuals who are illiterate.
6. Be culturally courteous with patients and participants. Speak with them respectfully as dictated by their culture (Using the formal ‘usted’ instead of informal ‘tu’ when addressing participants.)

This next list consists of recommendations that the researcher did not implement in the design, but that could make most studies involving with a similar population more successful. It was important to consider that many of the recommendations would be more attainable if there was research funding available. Looking back, the study was designed considering the researcher’s ability to fund it. Additionally, the following recommendations require sustained effort, as the

researcher suggest immersion and exposure to the patient population of interest to increase familiarity and comfort. Therefore, the investigator offers the following recommendations:

(B) Information for all regarding what the researcher thinks could have made the study more successful.

7. Be visible and available to your patient population. Speak to the community and give them an opportunity to know you, even if it is casual. Send students to do practica or volunteer activities that benefit the patient population you want to examine. This can be viewed as “giving-back” so the population understands your commitment to their welfare.
8. When you have built trust and rapport with the target population, speak with possible participants about your study. Explain in laymen’s terms and begin to advertise your study through word of mouth.
9. Verbal announcements and communications are most effective. Expect phone calls and answer many questions.
10. Social Media is an important new resource that can be used as recruitment. Utilize it wisely.
11. Do not give your participants extra work. Be as streamlined with study information, directions, parking, and instructions. If possible, select associates to be liaisons for participants (finding them in parking lot, etc.).
12. Ensure that study sessions can occur during business and non-business hours. This will open availability for those individuals who work during business hours.
13. Provide child care.
14. Provide transportation.

15. Select a battery of tests that has norms appropriate population. Do not rely on non-standardized, experimental tests that might not yield significant results.
16. If it exists, partner with a neuropsychological clinic that serves your patient population. It might be simpler to use their neuropsychological data and collect experimental data after this portion.

Limitations

All the limitations of this study should be considered as suggestions for possible research directions, especially regarding neuropsychological studies. Given that this was a post-hoc exploration of difficulties with the implementation of the original study, the current interpretation was limited by the memory of the researcher. As most qualitative data are gathered from the events witnessed by the researcher, there is a bias that must be expressed. The development of the dissertation did not follow a typical process as it was performed post-hoc after summarizing all available information. It was also largely influenced by the professional development of the researcher from graduate student, to doctoral candidate, to current clinical intern.

Conclusions

The researcher used Bronfenbrenner's model to examine and describe the influences that indirectly and directly affected participant recruitment and data collection. As the findings were conceptualized post-hoc, the researcher found similarities between the ecological theory and SRN framework used on clinical internship and thus combined them in his interpretation. That is to say, the researcher applied the same mechanism of conceptualization as the SRN model by

determining proximal processes (e.g., individual, relational, cultural, political) that contributed to his findings. The findings culminated in suggestions for best practices in conducting research with Latinos, though many of the recommendations could be applied to all individuals being recruited for similar types of research studies. This dissertation represents the first known case study to describe and analyze neuropsychological findings using an ecological systems perspective with Spanish-speaking patients living with HIV. Additionally, the researcher identified similarities within the ecological model and the SRN which highlights the importance of examining proximal processes across various systems in clinical and research settings. Finally, it highlighted the importance of considering cultural and social elements in the population of interest in research recruitment and data collection.

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Appendix A – Figures

Figure 1. Berg Card Sorting Test initiation screen.

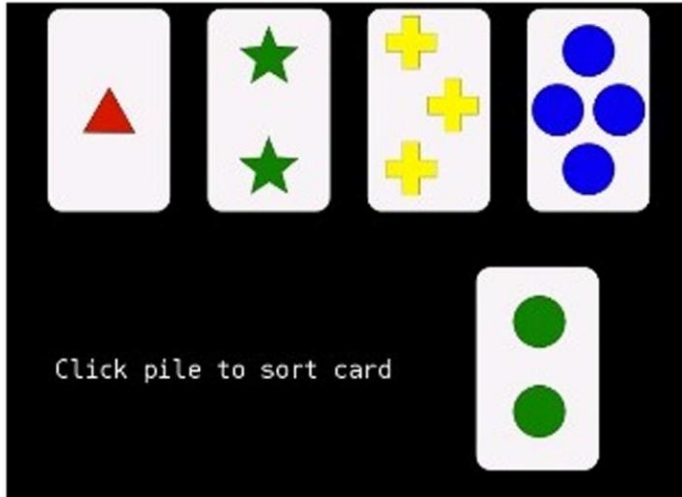


Figure 2. Transverse patterning stimuli. Stage 1 (A+, B-); Stage 2 (A+, B-), (B+, C-); Stage 3 (A+, B-), (B+, C-), (C+, A-).

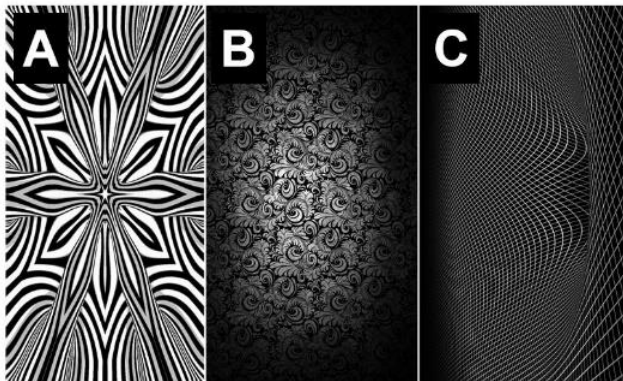


Figure 3. Reversal stimuli. Stage 1 (A+,B-); Stage 2 (A+,B-),(C+,D-); Stage 3 (A+,B-),(C+,D-), (E+,F-); Stage 4 (E-, F+); Stage 5 (E-,F+), (C-,D+); Stage 6 (E-,F+), (C-,D+), (A-,B+).

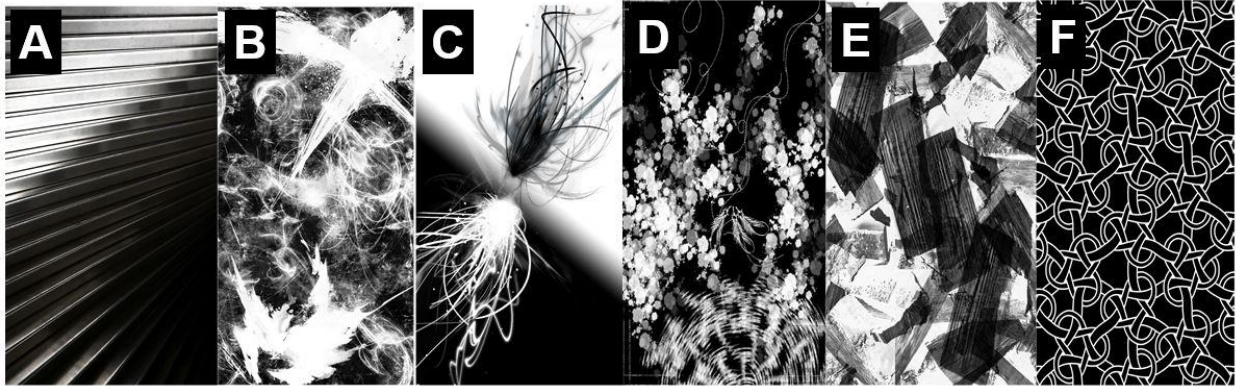
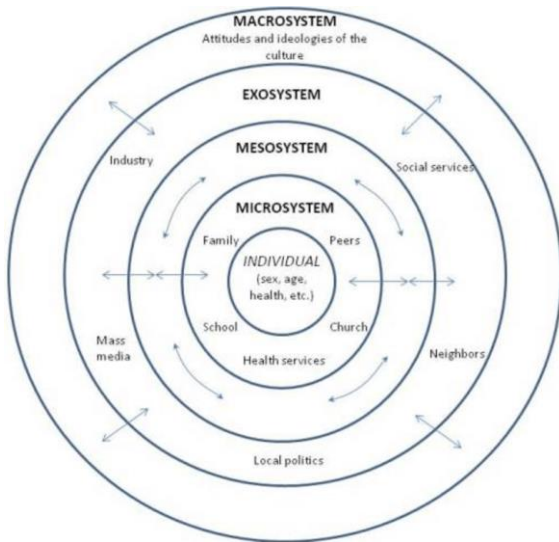


Figure 4. Bronfenbrenner's Ecological Systems Model.



Appendix B – Tables

Table 1. Demographic factors for study sample.

	Age	Men	Women	Ethnic Origin	Education in Years	Years Diagnosed	Years Taking Meds	Income in Dollars
Participants	M = 43 SD = 5.4 (Range 29-49 years old)	9	8	Mexican = 10 Puerto Rican = 7	M = 7.1 SD = 8.5 (Range 3-15 years)	M = 9.88 SD = 7.3 (Range 1-29 years)	M = 9.5 SD = 7.1 (Range 1 – 29 years)	M = 341.1 SD = 278 (Range 0 – 800 dollars)

Table 2. Demographics factors by groups of complete and incomplete data.

	Data Complete	Data Incomplete	Wilcoxon-Mann Whitney Test
Age	M = 42 SD = 6.5	M = 44 SD = 4.7	$p = .56$
Men	4	5	---
Women	3	5	---
Ethnicity	Mexico = 6 Puerto Rico = 1	Mexico = 4 Puerto Rico = 6	---
Education in years	M = 8.3 SD = 3.9	M = 6.3 SD = 3.02	$p = .29$
Years Diagnosed	M = 10.85 SD = 10.29	M = 9.2 SD = 4.78	$p = .69$
Years Taking Meds	M = 10.71 SD = 10.31	M = 8.6 SD = 4.14	$p = .73$
Income in Dollars	M = 314.14 SD = 348.57	M = 360 SD = 235.5	$p = .66$

Table 3. Hopkins Verbal Learning Test (HVLT) Memory Scores Corrected for Education using norms by Cherner and colleagues (2007).

HVLT Immediate Recall			
Participant	Raw Score	T Score	Descriptor
1	24	42	Average
2	22	50	Average
3	29	55	Average
4	21	41	Average
5	21	44	Average
6	27	54	Average
7	17	32	Borderline

HVLT Delayed Recall			
Participant	Raw Score	T Score	Descriptor
1	7	38	Low Avg.
2	8	50	Average
3	11	62	High Avg.
4	7	46	Average
5	6	45	Average
6	10	58	High Avg.
7	5	40	Low Avg.

HVLT Recognition			
Participant	Raw Score	T Score	Descriptor
1	12		WNL
2	11		WNL
3	11		WNL
4	10		WNL
5	9		WNL
6	11		WNL
7	9		WNL

Table 4. Brief Visuospatial Memory Test (BVMT) Memory Scores Corrected for Age and Education using norms by Cherner and colleagues (2007).

BVMT Immediate Recall			
Participant	Raw Score	T Score	Descriptor
1	17	33	Borderline
2	3	27	Impaired
3	30	57	Average
4	3	25	Impaired
5	0	33	Borderline
6	10	36	Borderline
7	31	77	V. Superior

BVMT Delayed Recall			
Participant	Raw Score	T Score	Descriptor
1	10	47	Average
2	2	36	Borderline
3	12	65	High Avg.
4	3	39	Low. Avg.
5	1	37	Low. Avg.
6	4	41	Low Avg.
7	11	73	V. Superior

BVMT Recognition			
Participant	Raw Score	T Score	Descriptor
1	4		WNL
2	2		Low
3	6		WNL
4	4		WNL
5	2		Low
6	6		WNL
7	5		WNL

Table 5. Medication Management Ability Assessment (MMAA) Raw Scores

MMAA Total Score	
Participant	Raw Score
1	32
2	25
3	33
4	28
5	20
6	27
7	17

MMAA Total Pills	
Participant	Raw Score
1	21
2	25
3	21
4	26
5	12
6	19
7	18

Table 6. Transverse Patterning Test and Reversal Test Raw Scores

Transverse Patterning Test	
Participant	Raw Score
1	500
2	500
3	90
4	500
5	500
6	500
7	500

Reversal Test	
Participant	Raw Score
1	134
2	298
3	190
4	500
5	500
6	500
7	500

Table 7. Berg's Card Sorting Test (BCST) Scores Corrected for Age and Education using norms by Artiola & Heaton (1996).

Participant	Total Trials			Total Correct			Perseverative Responses		
	Raw Score	T Score	Descriptor	Raw Score	T Score	Descriptor	Raw Score	T Score	Descriptor
1	128	41	Low Avg.	47	34	Borderline	79	27	Impaired
2	128	47	Average	38	37	Low Average	87	34	Borderline
3	128	41	Low Avg.	106	82	V. Superior	33	40	Low Average
4	128	47	Average	31	34	Borderline	97	30	Borderline
5	128	50	Average	26	30	Borderline	61	43	Average
6	119	62	High Avg.	102	85	V. Superior	28	51	Average
7	128	50	Average	98	86	V. Superior	21	60	High Avg.

Participant	Categories			Total Errors			Failures to Maintain Set	
	Raw Score	T Score	Descriptor	Raw Score	T Score	Descriptor	Raw Score	Percentile
1	1	30	Borderline	81	32	Borderline	0	<84
2	2	47	Average	97	32	Borderline	2	<84
3	6	63	High Avg.	22	55	Average	4	<84
4	1	38	Low Average	102	22	Impaired	1	<84
5	1	43	Average	102	28	Impaired	2	<84
6	6	71	V. Superior	17	68	Superior	1	<84
7	5	62	High Avg.	30	69	Superior	2	<84

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Appendix C – Curriculum Vitae

Contact Information

Clinical Psychology Intern

UCLA - The Semel Institute for Neuroscience and Behavior

Department of Psychiatry

(310) 225-4304

egracian@mednet.ucla.edu

Citizenship: USA

Research Interests

Cognitive predictors of conversion to Alzheimer's disease vs. Normal Aging.

Learning and Memory.

Clinical Interests

Assessment and diagnosis of pathological cognitive impairment in clinical populations.

Neuropsychological assessments in Spanish-speaking populations with cognitive impairment.

Education

PhD In Progress

University of Wisconsin-Milwaukee

Expected: July 2019

Clinical Psychology

Specializations: Health Psychology, Neuropsychology and Neuroscience

Department of Psychology

Advisors: Katie E. Mosack, PhD; David C. Osmon, PhD, ABPP.

Dissertation Title: The influence of proximal processes in recruitment and participation of

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monolingual Spanish-speaking Latinos/as living with HIV in neuropsychological research in Milwaukee: An ecological theory analysis from a Chicano cultural perspective.

Internship: *Adult Neuropsychology, UCLA – Semel Institute for Neuroscience and Behavior*

Post-Doctoral Fellowship: *Operation Mend: Neuropsychology of Trauma, Stress and Resilience, UCLA - Semel Institute for Neuroscience and Behavior (Effective: July 1, 2019)*

MA **San Diego State University** **August 2012**

Psychology

Specialization: Behavioral and Cognitive Neuroscience

Department of Psychology

Advisor: Paul E. Gilbert, PhD.

Thesis Title: Age-Related Changes in Spatial Pattern Separation: A Rodent Model of Healthy Aging.

BA with Honors **University of California, Irvine** **June 2009**

Psychology, Cum Laude, Departmental Honors

Specializations: Cognitive Science and Neuroscience

Department of Cognitive Sciences

Advisor: Mary-Louise Kean, PhD.

Thesis Title: Stereotype Threat in a Mental Rotation Task.

Peer-Reviewed Publications

3. **Gracian, E.I.**, Osmon, D.C & Mosack, K.E. (2016). Transverse Patterning, Aging, and Neuropsychological Correlates in Humans. *Hippocampus*, 26(12), 1633-1640.
2. **Gracian, E.I.**, Shelley, L.E., Morris, A.M., Gilbert, P.E. (2013). Age-related Changes in Place Learning for Adjacent and Separate Locations. *Neurobiology of Aging*, 34(10), 2304-09.
1. Maasberg, D.W., Shelley, L.E., **Gracian, E.I.**, Gilbert, P.E. (2011). Age-Related Differences in the Anticipation of Future Rewards. *Behavioural Brain Research*, 223, 371-375.

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Manuscripts (under review; revise/resubmit; in preparation)

Gracian, E.I., Resch, Z., Mosack, K.E., & Osmon, D.C. (revise/resubmit). Reversal learning, neuropsychological correlates, and aging in humans. *Neurobiology of Aging*.

Gracian, E.I., Resch, Z., Mosack, K.E., & Osmon, D.C. (in preparation). Pattern separation and its predictive validity of medication management ability. *Behavioural Brain Research*.

Gracian, E.I., Mosack, K.E., & Osmon, D.C. (in preparation). Non-uniform age-related differences and neuropsychological correlates of medication management ability and subjective memory complaints in cognitively normal older adults. *Applied Neuropsychology*.

Research Experience

Research Assistant University of Wisconsin-Milwaukee 8/14-present

Advisors: Katie E. Mosack, PhD; David C. Osmon, PhD, ABPP.

Department of Psychology

Cognitive deficits associated with normal aging

Neurocognition and medication management ability in healthy older adults

Neurocognition, medication management, and medication adherence in people living with HIV

Administering/Scoring Neuropsychological Assessments

Research Assistant University of Wisconsin-Milwaukee 10/17-6/18

Advisors: Krista M. Lisdahl, PhD.

Department of Psychology

Brain Imaging and Neuropsychology (BraIN) Laboratory

Adolescent Brain Cognitive Development (ABCD) Study

Translated study documents from English to Spanish

Conducted screening procedures and study sessions with Spanish-speaking parents in Spanish

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Conducted interviews to hire Spanish-speaking staff

Research Assistant **University of Wisconsin-Milwaukee** **8/12-8/14**

Advisor: Ira Driscoll, PhD.

Department of Psychology

Administered/Scored Neuropsychological Assessments

Cognitive impairments that could serve as early predictors of Alzheimer's disease onset

Cognition in middle and older age using behavioral, eye-tracking, and neuroimaging techniques

Eye-tracking using Applied Science Laboratories D6 eye tracking system

Computer programming using Presentation Software

Eye-tracking data analysis using EYENAL Analysis Software

Research Assistant **San Diego State University** **8/10-7/12**

Advisor: Paul E. Gilbert, PhD.

Department of Psychology

Center for Healthy Aging and Neurodegenerative Disease Research

Administered/Scored Standardized Neuropsychological Assessments

Learning and memory impairments in human and rodent models of healthy aging

Analyzed behavioral animal data using *Topscan* Software

Conference Posters

19. **Gracian, E.I.**, Kazakov, D.O., Wright, D.O., Austiff, M.B., Osmon, D.C., & Mosack, K.E. (2019, February). Non-uniform age-related differences, concurrent validity, and neuropsychological correlates of WebEXEC in cognitively normal older adults. International Neuropsychological Society, New York, NY.
18. **Gracian, E.I.**, Wright, D.O., Austiff, M.B., Osmon, D.C., & Mosack, K.E. (2018, October). Non-uniform age-related differences and neuropsychological correlates of subjective memory complaints in cognitively normal older adults. National Academy of Neuropsychology, New Orleans, LA.
17. **Gracian, E.I.**, Kazakov, D., Resch, Z., Austiff, M.B., Yang, B., Osmon, D.C., & Mosack,

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- K.E. (2018, February). Non-uniform age-related differences and neuropsychological correlates of medication management ability in cognitively normal adults. International Neuropsychological Society, Washington, DC.
16. **Gracian, E.I.**, Resch, Z., Austiff, M.B., Yang, B., Osmon, D.C., & Mosack, K.E. (2017, October). Memory and executive function contributions to medication management ability in cognitively normal younger and older adults. National Academy of Neuropsychology, Boston, MA.
15. **Gracian, E.I.**, Austiff, M.B., Cichon, J.C., Yang, B., Osmon, D.C., & Mosack, K.E. (2017, February). Transverse patterning performance is not uniform in cognitively normal older adults. International Neuropsychological Society, New Orleans, LA.
14. Resch, Z., **Gracian, E.I.**, Quasney, E., Sabsevitz, D.S., Binder, J.R., Mueller, W.M, & Swanson, S.J. (2017, February). Neuropsychological changes following frontal lobe resections in patients with epilepsy. International Neuropsychological Society, New Orleans, LA.
13. Blujus, J.K., Kaiver, C.M., **Gracian, E.I.**, Hannula, D.E., & Driscoll, I. (2016, November). Using eye movements to dissociate memory performance in normal and pathological aging. Society for Neuroscience, San Diego, CA.
12. **Gracian, E.I.**, Austiff, M.B., Cichon, J.C., Yang, B., Osmon, D.C., & Mosack, K.E. (2016, October). Reversal learning ability varies in cognitively normal older adults. National Academy of Neuropsychology Convention, Seattle, WA.
11. **Gracian, E.I.**, Austiff, M.B., Wright, D.O., & Mosack, K.E. (2016, February). Executive function and memory contributions to medication management ability in cognitively normal, older adults. International Neuropsychological Society Convention, Boston, MA.

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10. **Gracian, E.I.**, Austiff, M.B., & Mosack, K.E. (2015, November). A preliminary analysis of memory and executive function contributions to a medication management task in healthy, young adults. National Academy of Neuropsychology Convention, Austin, TX.
9. **Gracian, E.I.**, Austiff, M.B., Billig, A.K., Wandrey, R.L., de St. Aubin, E., & Mosack, K.E. (2015, May). Big 5 personality traits, religiosity, and conservative beliefs are not uniformly related to negative attitudes about gay men in two samples from a mid-size Midwestern city. Association for Psychological Science Convention, New York, NY.
8. **Gracian, E.I.**, Nowak, N.T., Awe, E., & Driscoll, I. (2014, November). Associations between reversal learning and regional brain volumes in middle age. Society for Neuroscience, Washington, DC.
7. Medina, L.D., **Gracian, E.I.**, Pirogovsky, E., Brusati, G., Gluhm, S., Bloom, B., Woods, S.P., Filoteo, V., & Gilbert, P.E. (2013, February). Prospective Memory Relates to Everyday Functioning in Older Adults but not in Younger Adults. International Neuropsychological Society, Waikola, HI.
6. **Gracian, E.I.**, Shelley, L.E., Morris, A., Najjar, A., & Gilbert, P.E. (2012, October). Age-related changes in spatial pattern separation in rats. Society for Neuroscience, New Orleans, LA.
5. Shelley, L.E., **Gracian, E.I.**, Greer, N., Maasberg., D.W., & Gilbert, P.E. (2012, October). Age-related differences in the detection of metric spatial change in rats. Society for Neuroscience, New Orleans, LA.
4. Holden, H.M., Toner, C.K., Pirogovsky, E., **Gracian, E.I.**, Kirwan, C.W., & Gilbert, P.E. (2012, October). Visual object pattern separation deficits vary in cognitively normal older adults. Society for Neuroscience, New Orleans, LA.

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3. **Gracian, E.I.**, Holden, H.M., Tolentino, J.C., Pirogovsky, E., Hoebel, C., Shelley, L.E., Maasberg, D.W., & Gilbert, P.E. (2011, November). Age-related changes in spatial and temporal pattern separation in nondemented older adults. Society for Neuroscience, Washington, DC.
2. Shelley, L., Maasberg, D.W., **Gracian, E.I.**, Greer, N., Guzman, K.L., Galleta, A.F., & Gilbert, P.E. (2011, November). Aging and Anticipation of Reward. Society for Neuroscience, Washington, DC.
1. Maasberg, D.W., **Gracian, E.I.**, Shelley, L.E., Guzman, K.L., Galleta, A.F., & Gilbert, P.E. (2011, November). Age-Related Changes in the Detection of Spatial Novelty. Society for Neuroscience, Washington, DC.

Clinical Experience

Psychology Intern **UCLA - Semel Institute** **7/18-present**
Division of Medical Psychology-Neuropsychology
Hispanic Neuropsychiatric Center of Excellence (HNCE)
Cultural Neuropsychology Program (CNP) and Medical Psychology Assessment Center (MPAC)
Adult Neuropsychology Intern: Advanced training in administration, scoring, interpretation and written documentation of findings from neuropsychological assessments, psychological inventories, and diagnostic interviews with clients (ages 18-90) experiencing a variety of neuropsychological (neurodegenerative disorders, dementias, memory disorders) and neurological (epilepsy, traumatic brain injuries, strokes) challenges in English and Spanish. Supervisors: Paola A. Suarez, PhD, Xavier E. Cagigas, PhD, Patricia Walshaw, PhD, Robert M. Bilder, PhD, ABPP-CN, and Nicholas Thaler, PhD, ABPP-CN.

Doctoral Trainee **United Community Center** **5/17-5/18**
Latino Geriatric Center / Memory Clinic
Advanced Practicum Student: The Latino Geriatric Center provides comprehensive services to Spanish-speaking elderly individuals with cognitive and physical impairments. Services in the Memory Clinic are provided by a neurologist and include semi-structured interviews and administration of cognitive screeners to older adults in low-income communities in Milwaukee, Wisconsin. Training focuses on tailoring case conceptualization skills, honing the process of developing recommendations, and providing feedback. Supervisors: Piero G. Antuono, MD.

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Doctoral Trainee

Medical College of Wisconsin

5/16-5/18

MCW Neuropsychology Clinic

Neuropsychology Practicum Student: Advanced training in administration, scoring, interpretation and written documentation of findings from neuropsychological assessments, psychological inventories, and diagnostic interviews with clients (ages 18-90) experiencing a variety of neuropsychological (neurodegenerative disorders, dementias, memory disorders) and neurological (epilepsy, traumatic brain injuries, strokes) challenges. Training also includes involvement in the development of a neuropsychological research database that documents trends and outcomes for patients with memory disorders and epilepsy. Supervisors: Julie A. Bobholz, PhD; Michael McCrea, PhD ABPP-CN; Lindsay Nelson, PhD; David S. Sabsevitz, PhD, ABPP; Sara J. Swanson, PhD, ABPP; Laura G. Umfleet, PsyD.

Doctoral Trainee

University of Wisconsin-Milwaukee

8/13-6/18

Learning Disabilities Clinic

08/17 – 08/18

Advanced Neuropsychometrician: Advanced training in administration, scoring, interpretation and written documentation of findings from psycho-diagnostic, psychoeducational, and neuropsychological assessments with adult clients (ages 18-65) to determine deficits and diagnoses related to intellectual disabilities, learning disabilities, and cognitive disorders. Training also includes involvement in the development of a neuropsychological research database that documents trends and outcomes for patients with learning disabilities, processing impairments, and attention disorders. Supervisors: David C. Osmon, PhD, ABPP.

Psychology Clinic

08/13 – 08/17

Assistant to the Director: Perform diagnostic interviews with prospective clients. Intake interviews include semi-structured and structured assessments to determine presenting problems and diagnoses. The process includes an evaluation of the cases to ensure client needs fit within the training scope of the clinic. This assessment also ensures that cases are assigned to clinical supervisors and therapists who are qualified to develop treatments to fit the clients' needs. Audits of clinical files to ensure quality and completeness are also performed. Supervisors: Stacey L. Nye, PhD; Bonita Klein-Tasman, PhD.

Student Therapist: Provide individual therapy to community clients in a low-cost (sliding fee) clinic. Diagnoses of adult therapy clients (ages 20-65) include depressive disorders, anxiety disorders (GAD, Social Phobia, and Panic Disorder), and adjustment disorders. Primary treatment modalities in cognitive-behavioral and behavioral therapies. Supervisors: Robyn Ridley, PhD; Christopher Martell, PhD, ABPP; Stacey Nye, PhD FAED.

Psychoeducational Assessments: Training in administration, scoring, interpretation and written/oral reporting of findings from psychological, personality, and neuropsychological assessments and clinical interviews with clients (ranging ages 7-30) experiencing a variety of intellectual (math, reading), psychological (depression, anxiety, personality disorders), cognitive

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(ADHD), and behavioral (oppositional defiant disorder) challenges. Supervisors: Han Joo, Lee, PhD; Kristin Smith, PhD; Bonita Klein-Tasman, PhD.

Student Coach

University of California, Irvine

9/08-9/10

Creating Options and Conquering Hurdles (C.O.A.C.H), Counseling Center

Life Coach: Assisted undergraduate students in accomplishing their academic, social, and personal goals. The primary goal was to provide students who are stressed, unmotivated or worried about their grades or life in general with a personal coach. The role of a life coach was to assess student needs, formulate a problem-solving plan, and mentor the student's progress until goals were achieved. Supervisor: Marikyo Adams, LCSW.

Student Grants - Funded

APAGS Psychological Science Diversity Research Grant -- \$1000

2017-2018

Project: Relationships among neurocognition, medication management ability, medication adherence, and biometric variables in monolingual Spanish-speaking Latinos/as living with HIV.

Advisors: Katie E. Mosack, PhD; David C. Osmon, PhD, ABPP.

This study examined the predictive validity of standardized measures of memory and executive function with medication adherence and biological measures of HIV in monolingual Spanish-speaking Latinos/as.

Senate Appropriations Committee (SAC) Grant -- \$3500

2016-2017

Project: 4th Annual Forum on Latino/a Affairs

The forum was a meeting place for Milwaukee's community members to discuss issues pertinent to the Latino community to understand their impact and identify possible solutions. This forum focused on minority stress and how it impacts Latinos/as in Milwaukee, especially in regard to LGBT issues, gentrification, and mental health stigma.

Graduate Student Committee: Gabriela Nagy, Enrique Gracian, Rachel Reinders.

Sigma Xi Grants-In-Aid of Research Award -- \$1000

2015-2017

Project: An examination of the validity of WebEXEC among individuals living with HIV.

Advisor: Katie E. Mosack, PhD.

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This study examined the validity of a short, self-report measure of executive functioning and its relation to standardized cognitive measures, medication management, and medication adherence in individuals living with HIV.

Senate Appropriations Committee (SAC) Grant -- \$3500 *2015-2016*

Project: 3rd Annual Forum on Latino/a Affairs

The forum was a meeting place for Milwaukee's community members to discuss issues pertinent to the Latino community to understand their impact and identify possible solutions. This forum focused on voting and voting behaviors in the Milwaukee Latino community as well as factors that influence voting in local, state, and national elections.

Graduate Student Committee: Gabriela Nagy, Enrique Gracian, Rachel Reinders.

Senate Appropriations Committee (SAC) Grant -- \$3500 *2014-2015*

Project: 2nd Annual Forum on Latino/a Affairs

The forum was a meeting place for Milwaukee's community members to discuss issues pertinent to the Latino community to understand their impact and identify possible solutions. This forum focused on leadership and civic engagement.

Graduate Student Committee: Gabriela Nagy, Rachel Reinders, Enrique Gracian.

Psychology Summer Research Fellowship -- \$3280 *2015*

Project: Use of eye movement monitoring to examine episodic memory in middle-aged and older adults

Advisor: Ira Driscoll, PhD.

This study used eye movement monitoring to examine episodic memory in middle-aged and older adults at risk for developing Alzheimer's disease.

Senate Appropriations Committee (SAC) Grant -- \$2700 *2013-2014*

Project: 1st Annual Forum on Latino/a Affairs

The forum was a meeting place for Milwaukee's community members to discuss issues pertinent to the Latino community to understand their impact and identify possible solutions. This forum focused on issues related to health and education.

Graduate Student Committee: Gabriela Nagy, Rachel Reinders, Enrique Gracian.

Sigma Xi Grants-In-Aid of Research Award -- \$1000 *2012-2013*

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Project: Eye-tracking may capture differences in memory deficits associated with normal aging and age-related neurodegenerative disease.

Advisor: Ira Driscoll, PhD.

This study examined the effects of aging and neurodegenerative disease on memory performance using eye-movement technology.

Department of Social Sciences Student Advancement Program -- \$10,000 *2010-2011*

Advisor: Marikyo Adams, LCSW.

This project was aimed at providing training in stress management, academic achievement, personal growth, and professional development to first year residents in the resident halls.

Undergraduate Research Opportunities Program (UROP) -- \$1000 *2007-2008*

Project: A Day in the Life: Inventing Engineers

Advisor: Carol Seron, PhD.

This study examined the motivational factors that contributed to students' academic achievement in engineering majors, and how this translated into success in engineering careers.

Teaching Assistant Experience

Neuropsychology	San Diego State University (1x)
Advanced Research Methods	San Diego State University (4x)
Human Sexuality	San Diego State University (1x)
Peer Counseling I, II, III	University of California, Irvine (1x)
Human Sexuality	University of California, Irvine (1x)
Clinical Psychology	University of California, Irvine (2x)
Abnormal Psychology	University of California, Irvine (2x)

Student Awards

<i>Ford Fellowship Honorable Mention</i>	2017	University of Wisconsin-Milwaukee
<i>Graduate Student Travel Grant Award</i>	2016	University of Wisconsin-Milwaukee

Enrique I. Gracian, M.A.

<i>Ford Fellowship Honorable Mention</i>	2015	University of Wisconsin-Milwaukee
<i>Advanced Opportunity Program Fellow</i>	2013-2016	University of Wisconsin-Milwaukee
<i>Chancellor's Graduate Student Award</i>	2012-2014	University of Wisconsin-Milwaukee
<i>Graduate Student Travel Grant Award</i>	2012	University of Wisconsin-Milwaukee
<i>Provost's Research Award</i>	2012	San Diego State University
<i>IRA Travel Grant Award</i>	2011	San Diego State University
<i>Student Scholar of Distinction</i>	2009	University of California, Irvine
<i>Dean's Honor List</i>	2006-2009	University of California, Irvine

Memberships

American Psychological Association (APA)

American Psychological Association of Graduate Students (APAGS)

Hispanic Neuropsychological Society (HNS)

International Neuropsychological Society (INS)

Midwestern Psychological Association (MPA)

National Academy of Neuropsychology (NAN)

Psi Chi Honor Society

Sigma Xi Honor Society

Society for Neuroscience (SfN)

Western Psychological Association (WPA)

Department/University Service

Diversity Committee Member – Psychology Department (2016-2017), UWM

Graduate Student Member – Forum on Latino Affairs Committee (2013-2017), UWM

Student Panelist – After McNair: How I developed my graduate research ideas (2016), UWM

Moderator/Student Panelist – National Ronald E. McNair Research Conference (2015), UWM

Student Panelist – After McNair: life as a graduate student (2015), UWM

Graduate Student Judge – UW-System Symposium for Undergraduate Research (2015), UWM

Enrique I. Gracian, M.A.

Student Speaker – Getting into graduate school in psychology (2012), UCI

Student Committee Member for Faculty Recruitment (2012), SDSU

Student Speaker – Graduate school in neuropsychology (2012), SDSU

Student Committee Member for Faculty Recruitment (2011), SDSU

Psi Chi Student Speaker – Getting into graduate school in psychology (2011), SDSU

Student Speaker – Welcome to the Psychology Graduate Program (2011), SDSU

Student Panel – How to survive your first year in graduate school (2011), SDSU

PsyMORE Student Mentor – (2011 - 2012), SDSU

Psi Chi Application Reviewer – (2009), UCI

Language Fluency

Spanish – Native Language

English – Fluent